Published in final edited form as:

Fam Cancer. 2018 October ; 17(4): 485–493. doi:10.1007/s10689-017-0065-z.

Adaptation of couples living with a high risk of breast/ovarian cancer and the association with risk-reducing surgery

Rachel Shapira^{1,4}, Erin Turbitt¹, Lori H. Erby¹, Barbara B. Biesecker¹, William M. P. Klein^{1,2}, Gillian W. Hooker³

¹Social and Behavioral Research Branch, National Human Genome Research Institute, National Institutes Health, Bethesda, MD, USA

²Behavioral Research Program, Division of Cancer Control & Population Sciences, National Cancer Center, Rockville, MD, USA

³Concert Genetics, Franklin, TN, USA

Abstract

Women who carry *BRCA1/2* mutations have a significantly elevated risk for breast and ovarian cancer. The positive test result and subsequent decisions about risk reducing behaviors can evoke distress, anxiety and worry. Psychological adaptation, or the process of coming to terms with the implications of a health threat, is an understudied construct in *BRCA1/2* carriers. Little is known about adaptation and how it relates to other aspects of living at high risk for cancer. Even less is understood about adaptation among partners of *BRCA1/2* carriers, and its relationship to adaptation in high risk individuals. Women at increased risk of breast/ovarian cancer ($N = 103$) and a subset of partners ($N = 39$) completed questionnaires that assessed risk management decisions (e.g. screening, risk-reducing surgery), dyadic coping, and the outcome of psychological adaptation. Women who had undergone risk-reducing mastectomy (RRM) had significantly higher levels of adaptation than those who had not ($t = 5.5$, $p < 0.001$, $d = 1.10$). Partners of women who had undergone RRM also had higher levels of adaptation than partners of women who had not undergone RRM ($t = 3.7$, $p = 0.01$, $d = 0.96$), though this association was not statistically significant when controlling for carriers' adaptation. Undergoing risk-reducing oophorectomy was not associated with adaptation for *BRCA1/2* carriers or their partners. Risk-reducing mastectomy is a significant event in the process of adapting to life at risk for hereditary cancer. Further, adaptation among partners is highly related to adaptation in carriers. These results aid in the understanding of the experience of couples living with cancer risk and the medical decisions related to adaptation.

Keywords

Breast cancer; BRCA1/2; Partner; Dyad; Risk reducing surgery; Adaptation

Rachel Shapira rshapira@mednet.ucla.edu.

⁴Present Address: UCLA Health, 200 Medical Plaza, Suite 122, Los Angeles, CA 90095, USA

Conflict of interest Gillian Hooker is employed by Concert Genetics and serves on the leadership team in her capacity as Vice President of Clinical Development. All other authors report no conflicts.

Introduction

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% [1]. Previous research has explored distress and anxiety related to the genetic testing process and the experience of carrying 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 [2]. Cancer-specific distress has also been related to medical decision making and the decision to undergo risk reducing surgery, highlighting the role that cancer worry can play in medical decision making [3].

Psychological adaptation is the process of coming to terms with the implications of a health threat [4]. 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 [5]. Based on Taylor's theory and Lazarus and Folkman's Transaction Model of Stress and Coping [6], the Psychological Adaptation Scale (PAS) is a scale designed and validated for the measurement of levels of adaptation at a single point in time in populations coping with major life stressors [7]. Previous research among *BRCA1/2* carriers has used changes in distress over time as a proxy for adaptation, but has not used more comprehensive measurements of the multidimensional construct of psychological adaptation, like the PAS [2]. Accordingly, research has focused on measuring negative impacts such as distress, or its absence, rather than on potentially positive psychological responses, thereby providing a partial picture of the complex experience of living at risk [8] and the impact that risk-related medical decisions like risk-reducing surgery can have on that process.

Carriers of *BRCA1/2* face many challenging risk-management decisions following a positive result. Risk-reducing surgeries, prophylactic mastectomy and oophorectomy, reduce the uncertainty that accompanies surveillance but bring their own challenges, such as influencing sexuality and body image [9, 10]. Previous research has explored risk-reducing mastectomy (RRM) and decision making around mastectomy in *BRCA1/2* carriers. Although most women have been shown to be satisfied overall, in one study, 23% of women experienced negative effects on sexual relationships following RRM [9]. A significant increase in problems with body image in the first 6 months following surgery has also been reported [10]. Despite these negative outcomes in the short term, research indicates that women who choose RRM later experience a decrease in psychological morbidity compared to their counterparts who choose high risk breast screening [11, 12].

When studying decision making and psychological outcomes in the context of hereditary breast and ovarian cancer, it is important to recognize that a high level of behavioral and emotional interdependence exists between a carrier and her partner [13]. Among partners of *BRCA1/2* carriers, studies have found that carriers' perceptions of spousal anxiety and support predict carriers' levels of distress [14], and levels of cancer-specific distress are correlated among women at high risk of breast/ovarian cancer and their partners [15]. It is largely unknown how closely aligned couples are in their coping strategies and levels of adaptation.

Evidence suggests that the genetic testing process may be distressing for some partners [13]. Further, partners are often integral to the decision-making process when considering RRM, and their emotions regarding the carriers risk status can, for some, carry a tremendous weight in determining the decision [16]. To date, only one small study has directly examined the impact of risk-reducing surgeries on partners [17]. In this qualitative study, the majority of partners did not feel the surgery had negatively affected their relationship, although a small number did note some relationship strains related to surgery [17].

BRCA1/2 carriers' anxiety and distress has also been shown to be associated with risk perception, and both are associated the decision to have RRM. Women undergoing RRM often have higher risk perceptions, compared to those who choose surveillance methods [12, 18, 19]. However, research has also shown that women with higher cancer risk perceptions may be overestimating their objective risk [11]. An association between perceived risk and psychological distress has been described among partners of women at increased risk for breast and ovarian cancer [13]. Given these associations, it is important to include risk perception as a variable in an exploration of the role of surgical status in adaptation.

Adaptation can be achieved in many ways including increasing perceived control and finding meaning. Adaptation in an individual does not happen in a vacuum, and it is important to recognize that partners are also adapting, and helping with adaptation. Much coping is dyadic in nature. Here we look at the convergence of dyadic coping in carriers and partners, and how such coping is related to adaptation to living at risk for hereditary cancer. We further hypothesized that cancer risk perception, surgery status, and dyadic coping will be related to adaptation to living at risk among carriers and their partners

Methods

Sample and recruitment

Women aged 18 years with a *BRCA1/2* mutation ('carriers') and their (male or female) partners were invited to participate. Carriers had no personal history of cancer and were required to speak and read English.

Participants were recruited through local and national support groups, email listservs and social media. Most participants learned of the study through the support organization FORCE: Facing Our Risk of Cancer Empowered, via local group and national emails, and Facebook. Individuals who were interested in participating were invited to visit the survey website hosted on SurveyMonkey, with 229 individuals (168 carriers and 61 partners) visiting the survey web-site. Carriers and their partners were asked to complete the surveys independently. All carriers responded to all measures on the survey regardless of whether their partner also participated.

Dependent measure

Psychological 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* to 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..." An overall adaptation score is calculated by generating a mean score of the 20 items. Cronbach's alpha was high (0.97 for carriers and 0.96 for partners).

Key independent measures

Medical history—Participants were asked about their family history of cancer. Medical history questions focused on cancer risk-management, including screening and risk-reducing surgery.

Feeling at risk—We assessed "feeling at risk" for developing breast and ovarian cancer, based on evidence that these kinds of risk perceptions are better predictors of behavior than more conventional measures of risk perception [20]. Participants were asked to rate their level of agreement or disagreement with two items (e.g. "I feel that I am going to get breast cancer" and "I feel that I am very vulnerable to breast cancer") on a 4-point scale (1 = *disagree strongly* to 4 = *agree strongly*). A mean value of the two items was calculated with high scores indicating high "feeling at risk". These items were reworded for partners (e.g. "I feel that my partner is going to get breast cancer"). Correlations between the two items were: $r = 0.61$, $p < 0.001$ for carriers' responses to breast cancer risk, $r = 0.63$, $p < 0.001$ for carriers' responses to ovarian cancer risk, $r = 0.64$, $p < 0.001$ for partners' responses to breast cancer risk, and $r = 0.41$, $p = 0.012$ for partners' responses to ovarian cancer risk.

Dyadic coping—The Dyadic Coping Inventory (DCI) was used to measure perceived communication and dyadic coping. The DCI is a 35-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* to 5 = *very often*) [21]. An example item was "I tell my partner openly how I feel and that I would appreciate his/her support". Responses to the 35 items were summed generating a possible range of 35 to 175. These items were identical for both carriers and partners. Cronbach's alpha scores were 0.80 for carriers and 0.95 for partners.

Demographics—Participants were asked to provide information about their income, age, gender, race/ethnicity, marital status, number of children, time since genetic testing and level of education.

Data analysis

The primary outcome variable, adaptation, was analyzed in both carriers and partners. 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 ≤ 0.02 were considered as candidates for inclusion in all subsequent multivariate regression models. Multivariate regression modeling was used to test for the association of key predictors on the outcome measure while controlling for covariates. Data were analyzed using SPSS 20.0, 2011.

This research was reviewed and approved by the National Human Genome Research Institute (NHGRI) Institutional Review Board (IRB) Protocol 13-HG-N134.

Results

Participant characteristics

Complete data were available from 103 *BRCA1/2* carriers; 39 had partners who also provided responses that were included in analyses. The average age of carriers was 39.7 ($SD = 10.1$). Participants were largely White (98%), non-Hispanic (95%), not of Ashkenazi Jewish descent (79%) and had a college or graduate degree (72%). Most were married (70%) and about two-thirds had at least one child (66%).

The partners' demographics were similar. Average age of partners was 41.9 ($SD = 11.2$). Most participants were White (97%), non-Hispanic (97%), not of Ashkenazi Jewish descent (92%) and had a college or graduate degree (77%). Most were married (69%) and 62% had at least one child (Table 1).

Medical history

Approximately half of the carriers had *BRCA1* mutations (48%); the remainder had *BRCA2* mutations. Most carriers had undergone at least one mammogram (87%) and breast MRI (83%). Although most had undergone ovarian screening, the rates were considerably smaller for both CA-125 (56%) and transvaginal ultrasound (63%). Close to half of all carriers had either undergone RRM (47%) or risk-reducing oophorectomy (RRO; 42%). Almost one-third of carriers had undergone both surgeries (31%). Of the 50 women who had not had RRM, 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 RRO, 47 (94.0%) would consider it. Of those 47 women, 40 (85.1%) said they definitely planned to have the surgery. The majority of women had at least one family member with breast (79%) or ovarian cancer (60%) (Table 2).

Feeling at risk of developing cancer

On average carriers somewhat agreed that they felt at risk for developing breast cancer ($M = 2.76$, $SD = 0.96$) on the 1–4 scale in which higher responses represented higher feelings of risk. Carriers felt at risk for developing ovarian cancer ($M = 2.13$, $SD = 0.87$), though this was lower than feelings of risk for breast cancer ($t = 4.89$, $p < 0.001$, $d = 0.63$). Carriers' feeling of risk was associated with surgery status. Those who had RRM had lower feelings of breast cancer risk compared to those who had not had RRM ($M = 2.15$, $SD = 0.21$ vs. $M = 3.25$, $SD = 0.13$; $p < 0.001$). Similarly, those who had RRO reported lower feelings of ovarian cancer risk compared to those who had not had RRO ($M = 1.90$, $SD = 0.17$ vs. $M = 2.91$, $SD = 0.11$; $p < 0.001$).

Partners' feeling at risk values for their partner developing cancer were similar to carrier values: with feeling at risk of their partner developing breast cancer a mean of 2.39 ($SD = 0.94$) and feeling at risk of their partner developing ovarian cancer a mean of 2.04 ($SD = 0.73$), these were not significantly different ($t = 1.84$, $p = 0.07$, $d = 0.35$).

Dyadic coping

Measures of dyadic coping were relatively high in carriers and partners. Means of dyadic coping were 132.76 ($SD = 17.40$) for carriers and 132.24 ($SD = 18.58$) for partners, of a possible score of 35–175.

Psychological adaptation

Mean adaptation score of women was 3.04 ($SD = 1.11$) and for partners was 2.81 ($SD = 0.93$), with 5 being the highest possible score. Mean adaptation score of the women whose partner provided responses to the survey was 2.92 ($SD = 1.21$).

Relational correlates of dyadic coping and adaptation between partners

Correlations were performed on the data provided by only those couples in which both members completed the survey ($n = 39$). Bivariate analysis showed high levels of concordance among couples across coping ($r = 0.60$, $p < 0.001$) and adaptation ($r = 0.52$, $p = 0.001$). High levels of concordance across couples were also present for feelings of risk for breast cancer ($r = 0.49$, $p = 0.003$) and ovarian cancer ($r = 0.54$, $p = 0.001$). Carrier's dyadic coping score was not correlated with either carriers' nor partners' adaptation scores ($r = 0.041$, $p = 0.79$; $r = 0.24$, $p = 0.15$ respectively) (Table 3).

Correlates of adaptation

Bivariate analyses demonstrated that adaptation was higher among woman who had undergone RRM, compared to those who had not ($t = 5.5$, $p < 0.001$, $d = 1.10$) (Fig.1). No other key independent measures were found to be associated with adaptation. Although an association was observed between carriers' breast surgery status and partners' adaptation scores ($t = 3.7$, $p = 0.01$, $d = 0.96$), this was not significant when controlling for carriers' adaptation scores.

A linear regression model was performed including surgical status, and demographic variables. In the overall model, only education level (such that those who were more highly educated had lower adaptation scores) and surgical status remained significant (Table 4).

Unlike RRM, we did not detect an association between RRO and adaptation for carriers or their partners (data not shown).

Discussion

This is the first study to tie a specific medical decision, namely risk reducing mastectomy, to the multi-dimensional concept of adaptation, using the Psychological Adaptation Scale (PAS) to examine psychological adaptation to living with a *BRCA1/2* gene mutation. Although studies have examined other psychological outcomes related to living with *BRCA1/2*, this is the first to use a multidimensional measure particularly designed to look at the construct of psychological adaptation as conceptualized by Taylor [5]. Using the PAS [7] to measure adaptation as an outcome, the mean score in carriers was 3.04 ($SD = 1.11$), near the scale midpoint of 3.0. This study is also the first to examine adaptation in partners of individuals living with genetic risk. The mean PAS score in partners was 2.72, again, near

the midpoint of the scale. 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 [22]. This study found that adaptation is positively associated with Quality of Life among adults with Neurofibromatosis 1, and points to a benefit of those who are better adapted.

A striking finding of the current study was the association between RRM and adaptation. Not only did those carriers who had undergone the surgery have higher levels of psychological adaptation than those who had not, but so did their partners. It is possible that undergoing RRM promotes adaptation; alternatively, it may be the case that women with higher adaptation are more likely to choose this surgery. It should be noted that the vast majority (96%) of women in our study who had not yet had RRM would consider doing so in the future. As such, we do not know how well adapted women are who feel firm in their decision not to have RRM. Also striking was the absence of an association between RRO and adaptation. This may provide insight into the RRM-adaptation relationship. Although similar numbers of carriers expressed that they would consider RRM and RRO, significantly more definitely planned to have RRO. The lack of definitive plans may play a role in the lower adaptation level among women who have not had RRM. Although RRO is recommended for *BRCA1/2* mutation positive women who have completed their childbearing, mastectomy is more of a value-based decision, with recommendations for clinicians centered more on discussing options with patients [19].

RRM for patients at risk of hereditary breast cancer has been performed as early as 1971 [23]. Recent evidence suggests that RRM decreases breast cancer risk by 85–100% and breast cancer mortality by 81–100%, compared to women who do not elect to undergo surgery [24]. Recent data suggest that close to half of all *BRCA1/2* carriers will undergo RRM in their lifetime [25]. Similarly, 47% of women in our study had undergone RRM.

Research has shown that women in the decision making process about RRM may perceive that the procedure will impair their quality of life [26]. The decision to undergo RRM is a complex one, and some women may not receive adequate counseling and information needed to make an informed decision [27]. A previous qualitative study showed that women considering RRM often turn to doctors to help make decisions [28]. The results of our study may help guide physicians in these conversations, and in the development of decision aids.

This study showed a high level of concordance between carriers' and partners' adaptation levels, as well as carriers' and partners' feelings of risk for cancer. This supports the notion that genetic testing for breast cancer risk and the related emotional consequences are interdependent between carriers and their partners. Dyadic coping was correlated among partners, suggesting the carriers and their partners in our study had high relationship quality. A previous Australian study of women at high risk of breast cancer and their partners showed a similar outcome [29]. Our study furthers this understanding through an exploration of the impact of various stressors, including RRM on adaptation.

Studies have shown that partners of women who undergo RRM can find it difficult to cope, though communicating these anxieties with their partner (the carrier) can assist with coping [30]. The data we present suggest a high level of dyadic coping, which could indicate good

communication between couples. We did not observe a relationship between dyadic coping and overall adaptation. This is in contrast to previous research among women with breast cancer which has shown high dyadic coping as an important factor in patient's adjustment [31]. It is possible our study was under-powered to detect an association, or because of a lack of variation in dyadic coping in our sample (a ceiling effect).

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.

As most participants were drawn from hereditary breast and ovarian cancer organizations, the study sample may be biased toward individuals who actively seek out support groups. As a result of the recruitment method, we do not know how many individuals had the opportunity to respond and how many declined. Therefore, it is not possible to calculate an accurate denominator. Demographically, there is a lack of racial and ethnic diversity in the study sample. Our results may not be generalizable to all *BRCA1/2* carriers and partners.

Finally, although the sample size of *BRCA1/2* carriers was adequate, the sample size of partners was relatively smaller. As partners were primarily recruited by the carriers, rather than reached directly, the study sample may be biased in favor of couples with certain characteristics, such as those with higher quality relationships.

Clinical implications

This study may have implications for the way genetic counselors and other health professionals (such as oncologists) discuss risk-reducing mastectomy with patients. An editorial in the New England Journal of Medicine considers psychosocial effects of RRM when physicians are assisting with decision-making among carriers, highlighting an appreciation of effects beyond clinical outcomes for carriers considering RRM [19]. However, the author focuses on alleviation of negative outcomes (such as stress and concern about cancer), rather than effects of positive outcomes, such as adaptation. The present study may aid in the creation of educational materials, directed at both professionals and patients, to help address discussion about psychosocial implications of RRM. 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. Prior research suggests that women who undergo RRM experience a decrease in psychological morbidity following the surgery [11], and satisfaction and quality of life were higher in women post-RRM [32]. These findings suggest that once the decision to undergo RRM has been made this will promote 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 [33]. However, their inclusion has often been seen as important because they serve 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.

Conclusion

Of the many variables examined, risk-reducing mastectomy proved to have the most salient relationship to adaptation in female *BRCA1/2* carriers. Further, we obtained a positive correlation between carrier and partner adaptation. These findings highlight the importance of including intimate partners in the genetic counseling and risk management decision-making processes. Moreover, the results aid in the understanding of the experience of women and couples living with cancer risk and the factors related to adaptation in the context of their intimate relationships.

Acknowledgements

This study was supported by the National Human Genome Research Institute Intramural Research Program.

References

1. Chen S, Parmigiani G (2007) Meta-analysis of BRCA1 and BRCA2 penetrance. *J Clin Oncol* 25(11):1329–1333 [PubMed: 17416853]
2. Hamilton JG, Lobel M, Moyer A (2009) Emotional distress following genetic testing for hereditary breast and ovarian cancer: a meta-analytic review. *Health Psychol* 28(4):510 [PubMed: 19594276]
3. Graves KD et al. (2007) Predictors and outcomes of contralateral prophylactic mastectomy among breast cancer survivors. *Breast Cancer Res Treat* 104(3):321–329 [PubMed: 17066320]
4. Biesecker B, Erby L (2008) Adaptation to living with a genetic condition or risk: a mini-review. *Clin Genet* 74(5):401–407 [PubMed: 18823383]
5. Taylor SE (1983) Adjustment to threatening events: A theory of cognitive adaptation. *Am Psychol* 38(11):1161
6. Lazarus RS, Folkman S (1984) *Stress, appraisal, and coping*. Springer, New York
7. Biesecker BB et al. (2013) Development and validation of the psychological adaptation scale (PAS): use in six studies of adaptation to a health condition or risk. *Patient Education Couns* 93(2):248–254
8. Aspinwall LG et al. (2013) Psychological aspects of hereditary cancer risk counseling and genetic testing, in *psychological aspects of cancer*. Springer, New York, pp 31–64
9. Frost MH et al. (2000) Long-term satisfaction and psychological and social function following bilateral prophylactic mastectomy. *Jama* 284(3):319–324 [PubMed: 10891963]
10. den Heijer M et al. (2012) Body image and psychological distress after prophylactic mastectomy and breast reconstruction in genetically predisposed women: a prospective long-term follow-up study. *Eur J Cancer* 48(9):1263–1268 [PubMed: 22105017]
11. Hatcher MB, Fallowfield L, A'Hern R (2001) The psychosocial impact of bilateral prophylactic mastectomy: prospective study using questionnaires and semistructured interviews. *BMJ* 322(7278):76 [PubMed: 11154619]
12. Glassey R et al. (2016) Decision making, psychological wellbeing and psychosocial outcomes for high risk women who choose to undergo bilateral prophylactic mastectomy: a review of the literature. *Breast* 28:130–135 [PubMed: 27318167]
13. Sherman KA, Kasparian NA, Mireskandari S (2010) Psychological adjustment among male partners in response to women's breast/ovarian cancer risk: a theoretical review of the literature. *Psycho-Oncology* 19(1):1–11 [PubMed: 19472298]
14. Wylie JE, Smith KR, Botkin JR (2003) Effects of spouses on distress experienced by BRCA1 mutation carriers over time. *Am J Med Genet C* 119:35–44

15. Mireskandari S et al. (2007) Psychological adjustment among partners of women at high risk of developing breast/ovarian cancer. *Genet Med* 9(5):311–320 [PubMed: 17505209]
16. Hoskins LM, Roy KM, Greene MH (2012) Toward a new understanding of risk perception among young female BRCA1/2 previvors. *Families Systems Health* 30(1):32
17. Lloyd S et al. (1999) Understanding the experience of prophylactic bilateral mastectomy: a qualitative study of ten women. *Psycho-oncology* 9(6):473–485
18. van Driel C et al. (2016) Psychological factors associated with the intention to choose for risk-reducing mastectomy in family cancer clinic attendees. *Breast* 30:66–72 [PubMed: 27639031]
19. Hartmann LC, Lindor NM (2016) The role of risk-reducing surgery in hereditary breast and ovarian cancer. *N Engl J Med* 374(5):454–468 [PubMed: 26840135]
20. Weinstein ND et al. (2007) Risk perceptions: assessment and relationship to influenza vaccination. *Health Psychol* 26(2):146 [PubMed: 17385965]
21. Ledermann T et al. (2010) Psychometrics of the Dyadic Coping Inventory in three language groups. *Swiss J Psychol* 69(4):201
22. Cohen JS (2009) Adaptation and quality of life among adults with Neurofibromatosis type 1. Unpublished ScM thesis, Johns Hopkins University, Baltimore
23. Lynch HT, Krush AJ (1971) Genetic predictability in breast cancer risk: surgical implications. *Arch Surg* 103(1):84–88 [PubMed: 5088439]
24. Nelson HD et al. (2014) Risk assessment, genetic counseling, and genetic testing for BRCA-related cancer in women: a systematic review to update the US Preventive Services Task Force recommendation. *Ann Intern Med* 160(4):255–266 [PubMed: 24366442]
25. Chai X et al. (2014) Use of risk-reducing surgeries in a prospective cohort of 1,499 BRCA1 and BRCA2 mutation carriers. *Breast Cancer Res Treat* 148(2):397–406 [PubMed: 25311111]
26. Wagner TMU, Möslinger R, Langbauer G, Ahner R (2000) Attitude towards prophylactic surgery and effects of genetic counselling in families with BRCA mutations. *Br J Cancer* 82(7):1249 [PubMed: 10755396]
27. Morgan D et al. (2010) Perceptions of high-risk care and barriers to care among women at risk for hereditary breast and ovarian cancer following genetic counseling in the community setting. *J Genet Couns* 19(1):44–54 [PubMed: 19809867]
28. Klitzman R, Chung W (2010) The process of deciding about prophylactic surgery for breast and ovarian cancer: Patient questions, uncertainties, and communication. *Am J Med Genet A* 152A(1):52–66 [PubMed: 20014126]
29. Watts KJ et al. (2011) Predictors of relationship adjustment among couples coping with a high risk of developing breast/ovarian cancer. *Psychol Health* 26(sup1):21–39 [PubMed: 20936567]
30. Rowland E, Metcalfe A (2014) A systematic review of men's experiences of their partner's mastectomy: coping with altered bodies. *Psychooncology* 23(9):963–974 [PubMed: 24800690]
31. Ben-Zur H, Gilbar O, Lev S (2001) Coping with breast cancer: patient, spouse, and dyad models. *Psychosom Med* 63(1):32–39 [PubMed: 11211062]
32. Hooker GW et al. (2014) Long-term satisfaction and quality of life following risk reducing surgery in BRCA1/2 mutation carriers. *Hereditary Cancer Clin Pract* 12(1):1
33. Mireskandari S et al. (2006) Evaluation of the needs and concerns of partners of women at high risk of developing breast/ovarian cancer. *Psycho-Oncology* 15(2):96–108 [PubMed: 15880639]

Fig. 1. Mean adaptation scores in carriers who have undergone risk reducing mastectomy (n = 48) versus carriers who have not (n = 50). Plotted are the mean PAS scores with 95% Confidence Intervals

Table 1

Participant characteristics of women and partners

Characteristic	Carrier; N = 103 n (%)	Carrier if partner data avail- ableN = 39 n (%)	Partners; N = 39 n (%)
Age			
< 25	4 (4)	2 (5)	2 (5)
25–39	42 (41)	18 (46)	15 (39)
40	46 (44)	19 (49)	19 (49)
Not provided	1 (1)		3 (7)
Race ^a			
White/Caucasian	101 (98)	36 (92)	38 (97)
Black/African American	1 (1)	1 (3)	0 (0)
Asian	1 (1)	1 (3)	0 (0)
Native American	2 (2)	1 (3)	1 (3)
Ethnicity			
Not Hispanic or Latino	98 (95)	37 (95)	38 (97)
Hispanic or Latino	5 (5)	2 (5)	1 (3)
Ashkenazi Jewish			
Yes	22 (21)	9 (23)	3 (8)
No/don't know	81 (79)	30 (77)	36 (92)
Highest level of education			
High school/GED	2 (2)	1 (3)	3 (7)
Technical school	5 (5)	0 (0)	2 (5)
Some college	12 (11)	3 (8)	1 (3)
Completed college	41 (40)	20 (51)	18 (46)
Post-graduate	33 (32)	14 (36)	12 (31)
Not provided	10 (10)	1 (2)	3 (8)
Relationship status			
In a relationship, not living together	4 (4)	3 (8)	3 (8)
In a relationship, living together	10 (10)	3 (8)	3 (8)
Engaged	2 (2)	1 (2)	1 (2)
Married	72 (70)	29 (74)	27 (69)

Characteristic	Carrier; N = 103 n (%)	Carrier if partner data available ^a N = 39 n (%)	Partners; N = 39 n (%)
Civil union/domestic partnership	4 (4)	2 (5)	2 (5)
Not provided	10 (10)	1 (3)	3 (8)
Biological children ^a			
Daughters	43 (42)	24 (62)	13 (33)
Sons	45 (44)	26 (67)	14 (36)
No children	34 (33)	19 (49)	15 (38)
Location			
United States	88 (85)	35 (90)	35 (90)
Other	15 (15)	4 (10)	4 (10)
Years with current partner			
< 10	29 (28)	14 (36)	14 (36)
10–20	45 (44)	15 (38)	13 (33)
> 20	18 (17)	9 (23)	9 (23)
Not provided	10 (10)	1 (3)	3 (8)
Time since genetic test (years)			
Range	0–13	0–10	
Mean (SD)	3.2 (3.0)	3.2 (2.8)	

^aParticipants could select more than one response

Table 2

Carriers' responses to medical history questions

Item	Frequency N = 103 n (%)	Carrier if partner data available N = 39 n (%)
Genetic testing		
<i>BRCA1</i> mutation	50 (49)	18 (46)
<i>BRCA2</i> mutation	52 (50)	21 (54)
Not provided	1 (1)	
Screening (has had)		
Mammography	90 (87)	37 (95)
Breast MRI	85 (83)	35 (90)
CA-125	58 (56)	23 (59)
TVUS	65 (63)	26 (67)
Risk-reducing surgery (has had)		
Bilateral mastectomy	48 (47)	17 (44)
Bilateral oophorectomy	43 (42)	17 (44)
Both mastectomy and oophorectomy	32 (31)	10 (26)
Family history		
At least one family member with breast cancer	81 (79)	36 (92)
At least one family member with ovarian cancer	62 (60)	23 (59)
Family member/s with breast and ovarian cancer	47 (46)	13 (33)

Table 3

Carrier's and partners' scores on dyadic coping and adaptation

Measure, possible range	Carrier		Carrier if partner data available		Partner	
	N	Mean (SD)	N	Mean (SD)	N	Mean (SD)
Dyadic coping, 35–175	95	132.76 (17.40)	38	137.24 (17.24)	36	132.24 (18.58)
Adaptation (PAS), 1–5	105	3.04 (1.11)	39	2.92 (1.21)	39	2.81 (0.93)

No significant differences between the scores of total carrier group compared to scores of subgroup of carriers whose partner responded to survey

Table 4

Linear regression of adaptation (PAS) with all variables stratified by RRM status

Variable	Standardized beta	p value
Highest level of education	– 0.23	0.013
Feeling at risk to breast cancer	– 0.12	0.30
Had RRM	0.38	< 0.001

Variables included in the model were significant in bivariate analyses. Education was collapsed to three categories: some college or less, college educated, postgraduate