



Published in final edited form as:

*Fam Cancer*. 2018 July ; 17(3): 351–360. doi:10.1007/s10689-017-0059-x.

## Information and support needs of young women regarding breast cancer risk and genetic testing: adapting effective interventions for a novel population

Suzanne C. O'Neill<sup>1</sup>, Chalanda Evans<sup>1</sup>, Rebekah J. Hamilton<sup>2</sup>, Beth N. Peshkin<sup>1</sup>, Claudine Isaacs<sup>3</sup>, Sue Friedman<sup>4</sup>, Kenneth P. Tercyak<sup>1</sup>

<sup>1</sup>Lombardi Comprehensive Cancer Center, Georgetown University Medical Center, 3300 Whitehaven Street, NW, Suite 4100, Washington, DC 20007, USA

<sup>2</sup>Armour Academic Center, College of Nursing, Rush University, 600 S. Paulina Street, Suite 1080, Chicago, IL 60612, USA

<sup>3</sup>Lombardi Comprehensive Cancer Center, Georgetown University, 3800 Reservoir Road, NW, Washington, DC 20007, USA

<sup>4</sup>FORCE, Inc., 16057 Tampa Palms Blvd. W, PMB #373, Tampa, FL 33647, USA

### Abstract

Young women from hereditary breast and ovarian cancer (HBOC) families face a unique set of challenges in managing their HBOC risk, where obtaining essential information to inform decision making is key. Previous work suggests that this need for specific health information also comes at a time of heightened distress and greater individuation from family. In this report, we describe our adaptation of a previously-studied behavioral intervention for this population, utilizing a systematic approach outlined by the Centers for Disease Control and Prevention. First, we assessed the information needs and levels of distress in this population and correlates of this distress. These data then were used to inform the adaptation and piloting of a three-session telephone-based peer coaching intervention. One hundred young women (M age = 25 years) who were first or second degree relatives of *BRCA1/2* mutation carriers participated. Sixty-three percent of the sample endorsed unmet HBOC information needs and they, on average, reported moderate levels of cancer-related distress (M = 21.9, SD= 14.6). Greater familial disruption was associated with greater cancer-related distress in multivariable models ( $p < .05$ ). Ten women who participated in the survey completed the intervention pilot. They reported lower distress from pre- to post- (15.8 vs. 12.0), as well as significantly lower decisional conflict ( $p < .05$ ) and greater endorsement of an array of healthy coping strategies (i.e., active coping, instrumental coping, positive reframing, planning,  $p$ 's < .05). Our survey results suggest that young adult women from HBOC families have unmet cancer genetic information and support needs. Our pilot intervention was able to reduce levels of decisional conflict and promote the use of effective coping strategies. This approach needs to be further tested in a larger randomized trial.

## Keywords

BRCA; Breast; Women; Intervention; Peer; Telephone

---

## Background

Most hereditary breast and ovarian cancer (HBOC) is attributable to *BRCA1/2* mutations conferring a 40–75% lifetime disease risk [1, 2]. Widespread use of breast cancer risk assessment/genetic testing (BCRA/GT) has allowed thousands of women and men from HBOC families to learn their carrier status [3-5]. Many of these carriers have female young adult relatives (i.e., sisters, cousins, daughters, nieces) at high risk of harboring this familial mutation. These young adult relatives often live much of their lives knowing that they are at heightened risk for carrying this genetic risk themselves [6, 7]. Guidelines suggest that genetic testing should begin at age 18 or later due to limited medical benefit and potential psychosocial harm, whereas genetic counseling and breast cancer risk assessment for women age 18 + is recommended as the standard of care [8-10].

BCRA/GT among young female relatives aged 18–25 may provide many benefits. Testing provides definitive positive [carrier of the familial mutation (“carrier”)] or negative results [not carrying this mutation (“true negative” and close to population risk)] [11]. Carriers can manage their risk through surgical interventions that greatly reduce the chances of breast/ovarian cancer mortality [12]. Definitive risk information not only informs medical management, but also could affect the timing of lifecycle events, such as education, employment, partnering, and childbearing. It is also likely to influence psychosocial adaptation to HBOC. However, *BRCA1/2* testing may also present clinical dilemmas [13]. Even though these women face high lifetime breast cancer risks (approximately 50%), young women with *BRCA1/2* mutations face relatively low 10-year breast cancer risks (1–2%) [14]. Risk management via surgery or screening are available, but are not typically utilized at this age [15]. Previous research by our team and others [7, 16-19] suggests that these short- vs. long-term tradeoffs for managing one’s health are associated with increased distress in this population, with limited sources of informational or social support to guide young women’s planning and adaptation. These data suggest the need for supportive intervention in this population, but there are limited data to bring to bear how and when to intervene. This includes quantifying young women’s distress and factors associated with distress, as well as the information and support needs in this population. Moreover, the important role of social support to protect young women has not been fully considered. Family and friends provide important informational and social support to young women, but that they could potentially benefit from the support of informed peers who have faced similar cancer risks [7, 16-19].

There are few manualized interventions designed to support members of HBOC families. Telephone-counseling interventions focused on coping and skill building led by peers [20] and Master’s level counselors [21, 22] have shown promise in reducing distress among female *BRCA1/2* mutation carriers. These prior interventions were adjuncts to comprehensive genetic counseling and focused on carriers, many of whom were older than

our target group and cancer-affected. Results of these trials suggest a peer-coach, telephone-based intervention could be a promising approach for young women from HBOC families. Peer support is a growing component of our healthcare landscape [23], with low cost [24], and has demonstrated beneficial effects of social support on patient health and well-being [25]. A Cochrane review concluded that telephone-based peer support is widely available, and more rigorous research on its effects are needed. Available data provided evidence of efficacy, such as increasing women's cancer screening, reducing their cardiovascular risks, and helping postpartum women with depression [26]. Women with HBOC risk, in particular, turn to peer support for anticipatory guidance about medical decisions and experiential knowledge from a trusted source [27]. However, intervention content developed for primarily older mutation carriers would need to be adapted to meet the needs of this population, such as their younger age, negative cancer history and competing demands that could limit their participation in a lengthy intervention [28]. These changes are best made by applying a systematic and empirical approach.

The Centers for Disease Control and Prevention (CDC) has outlined a systematic approach for adapting evidence-based behavioral interventions to new settings and populations. These include assessment of the population, selection of an intervention, adaptation of the intervention, piloting and implementation [29]. In the report, we describe our systematic intervention adaptation in three steps. First, we quantitatively describe the needs of our population, including the levels of distress and correlates of greater distress, as well as the information and support needs of young women from HBOC families. These data informed our systematic adaptation of a previously-studied intervention [21, 22] to fit the context, risks, and unique circumstances of young adult women. Finally, we piloted this adapted intervention in a subset of our target population (N = 10). We gathered mixed methods data to speak to the intervention's feasibility, acceptability and initial efficacy in improving psychosocial outcomes.

## Methods

### Participants

One hundred young women (M age = 25 years) who were first or second degree relatives of *BRCA1/2* carriers participated. Participants were recruited in two ways. Eligible young women aged 18–30 who may have previously undergone *BRCA1/2* testing were identified by first or second-degree male or female relatives who carried *BRCA1* or *BRCA2*. However, they were also eligible if they did not undergo testing. Male and female index carriers were recruited from research and clinical registries at a comprehensive cancer center and active for research recontact. Eligible young women were contacted by a project manager (CE) after being identified by index carriers with permission for contact. Young women also were reached directly for research through the website of a national nonprofit (Facing Our Risk of Cancer Empowered-FORCE). Regardless of method of recruitment, young women completed a telephone survey that lasted about 30 min. Participants received a \$20 gift card for participating.

Several months after completing the survey (mean time = 10.9 months), a subset of participants was recontacted to participate in our intervention pilot. Women were

approached sequentially, beginning with the most recent participant in the survey and working backwards. Of the 18 women approached to complete the pilot intervention, ten consented to participation (56% recruitment rate). Those who consented were younger (26.5 vs. 28.6,  $t = 2.58$ ,  $p < .05$ ) than those who did not enroll. They did not differ on any psychosocial or clinical variables. Most participants were White ( $N = 7$ ) and single/unmarried ( $N = 8$ ), two were Latina, and six were of Ashkenazi Jewish descent. Six had tested positive for their familial mutation, two tested negative and two had not been tested. All reported having commercial health insurance. Participants averaged 2.4 cancer-affected relatives (range 1–4; mothers, aunts, grandmothers) and the M age of the youngest affected relative was 43 (range 35–61 years).

Women who agreed completed additional consent and an online baseline survey. Following the baseline, they were connected to a peer counselor, who had initial contact with the participant within a few days after the baseline ( $M = 10$  days,  $SD = 4.32$ , range 5–18). The peer coach administered the three sessions of the intervention (mean time = 25.7 min each) via telephone and were audio recorded. Each session occurred with approximately a week in between each session ( $M = 8.83$  days,  $SD = 4.53$ , range 3–20). The participant and peer coach managed their availability via email and/or phone. If the participant was unavailable at the scheduled time, a message was left and the session was rescheduled. The peer coach was provided with the name and contact information for the participant, but not other details from their initial or baseline intervention survey, such as distress level or unmet needs. Upon completion, the participants were contacted for a post-intervention survey and debrief by the study project manager (CE) that was also audio recorded.

### Independent study variables: assessment

**Sociodemographic and medical variables**—Participants self-reported their age, race, education, and marital status. We also assessed the history of cancer in the family, including total number of relatives affected with breast or ovarian cancer and the ages of diagnosis, and whether the participant had received genetic testing for their familial mutation and the result of this testing.

**Familial disruption**—The Brief FAM: Self-Rating Scale is a valid and reliable ( $\alpha = 0.82$ ) 14-item scale used to assess the participants' perspective of how they function within their family. Participants indicated the degree to which they agreed with statements such as "My family and I usually see our problems the same way" and "When I'm upset, my family knows what is bothering me" on a 4-point Likert response (1 = strongly agree) to (4 = strongly disagree). Mean scores can be converted to T-scores, with a T-score of 50 representing average family difficulties and scores lower than 50 representing fewer than average difficulties.

**Perceived peer support**—The Perceived Social Support from Friends is a valid [30] and reliable ( $\alpha = 0.71$ ) 20-item scale. Participants indicated their perceived availability of social support from friends (1 = yes) to (0 = no). Scores range from 0 to 20, with higher scores indicating greater support.

**Perceived cancer risk**—Participants indicated their perceived risk of cancer by responding to the item, “Compared to other people your age, what do you think your chances are of developing cancer in the future?” on a 1 (no chance) to 7 (certain to happen) scale.

**Satisfaction with information**—Participants indicated their satisfaction with HBOC information using a reliable ( $\alpha = 0.82$ ), 8-item measure scored on a 5-point scale (1 = strongly disagree) to (5 = strongly agree). Items were reverse scored where appropriate and summed to create an overall score ranging from 8 to 40, with higher scores indicating higher satisfaction.

#### **Dependent study variable: assessment**

**Cancer-related distress**—The Impact of Event Scale (IES) is a reliable ( $\alpha = 0.88$ ) 15-item Likert-type scale, with two subscales that measure intrusive and avoidant ideation. Participants were asked to consider how frequently each item applied to them over the past 7 days on a 4-point scale (0 = not at all) to (5 = often). The IES has been widely used to measure the impact of being at increased cancer risk. A cut-off score of 33 identifies patients with symptoms in the clinical range [31].

#### **Pilot study variables**

Participants completed each measure before and after intervention participation. The baseline survey was completed online and the post-intervention survey was completed by phone.

**Distress**—The IES again was used to assess cancer-related distress and demonstrated strong internal consistency at baseline ( $\alpha = 0.90$ ) and follow-up ( $\alpha = 0.86$ ).

**Decisional conflict**—The Decisional-Conflict Scale (DCS) is a valid ( $\alpha = 0.90$ – $0.93$ ) 12-item measure used to assess conflict with breast cancer risk management decision-making on a 5-point scale (1 = strongly disagree) to (5 = strongly agree) [32].

**Coping**—Participants indicated how often they used 13 coping strategies (active coping, planning, using emotional support, using instrumental support, positive reframing, acceptance, humor, religion, self-distraction, self-blame, venting, alcohol/drug use, and behavioral disengagement) to manage their cancer risk using Brief COPE. Each strategy was measured with two items rated on the scale ranging from 0 (not at all) to 3 (a lot) [33]. The Denial subscale was excluded due to low reliability. Reliability of the remaining coping scales was adequate ( $\alpha = 0.60$ – $0.95$ ).

**Appraisals**—Primary and secondary appraisals were assessed using Halbert et al.'s [34] 5-item scales developed to assess appraisals related to HBOC risk. Participants responded on a 4-point scale (1 = not at all) to (4 = very) to indicate how stressful they found their cancer risk (primary appraisals) and how confident they felt coping with their risk (secondary appraisals). Scales were reliable at both time points ( $\alpha = 0.73$ – $0.86$ ).

**Process outcomes**—We gathered information at follow-up regarding several domains of satisfaction. This included how helpful the sessions were, how much the program met their needs related to making decisions about managing their risk, and their overall satisfaction with the program (1 = not at all to 4 = very).

### Statistical analysis

For the assessment phase of our research, descriptive statistics and bivariate analyses characterized the study sample and identified independent variables associated with distress. Independent variables associated at  $p < .10$  were then regressed onto the dependent variable in a multivariable linear regression model with hierarchical variable entry. For the intervention phase, means and standard deviations were generated. Paired-sample  $t$  tests were used to assess mean differences across time. Data were analyzed using SPSS 22.0.

## Results

### Participant characteristics

Table 1 displays characteristics of study participants. Participants were, on average, about 26 years old, predominantly White race (75%), were in college or had graduated from college, and were single (70%). Most (71%) had already received genetic testing for the *BRCA1/2* mutation segregating in their families; most of these (62/71) had tested positive. They averaged three breast or ovarian cancer cancer-affected relatives. The average age of the youngest family member to be diagnosed with one of these cancers was 43 years. None of the participants in this study had a personal cancer history.

### Step one: quantifying information and support needs

Overall, participants reported lower than average levels of familial disruption when compared to the norms ( $M = 14.9$ ,  $SD = 4.1$ ;  $T\text{-score} = 46$ ), and strong peer support ( $M = 17.1/20.0$ ,  $SD = 3.2$ ). They reported moderate levels of cancer-related distress ( $M = 21.9$ ,  $SD = 14.6$ ), and overall, perceived themselves to be likely to develop cancer in the future ( $M = 5.1/7$ ,  $SD = 1.2$ ).

With respect to participants' information needs (Table 1), 63% of the sample indicated at least one unmet need. Participants reported experiencing relatively high levels of control over how and what to learn about their health in general ( $M = 4.1/5.0$ ,  $SD = 1.0$ ) and awareness for what they wanted to learn with regards to *BRCA1/2* ( $M = 4.0/5.0$ ,  $SD = 0.9$ ). However, there was lower endorsement for items that addressed their satisfaction for how they currently learn about their health ( $M = 3.5/5.0$ ,  $SD = 0.9$ ) and their ability to access information related to *BRCA1/2* ( $M = 3.4/5.0$ ,  $SD = 1.1$ ).

As seen in Table 2, variables related to distress in bivariate analyses included lower satisfaction with information ( $r = -.19$ ,  $p < .06$ ), greater familial dysfunction ( $r = .30$ ,  $p < .01$ ), lower perceived peer support ( $r = -.19$ ,  $p < .06$ ) and greater perceived cancer risk ( $r = -.19$ ,  $p < .06$ ). Other variables, such as those related to cancer family history, were not associated with our outcome. These were excluded from further analysis.

We modeled the association between satisfaction with information, familial dysfunction, peer support and perceived risk on distress (Table 3). Only greater familial disruption predicted greater cancer-related distress (standardized  $\beta = 0.23$ ,  $p < .05$ ).

### Step two: systematic adaptation

We applied these data to a number of steps to support adaptation of materials and methods from a previously-studied intervention. First, we consulted the lead investigators of the trial as well as the trial's lead genetic counselor about strategies to adopt and adapt the intervention for our target population. This resulted in retaining the main trial outcomes of distress and incorporating decision making, streamlining the number of sessions, session length and supporting workbook materials, adopting peer coaches as interventionists, and incorporating peer training and fidelity protocols under the supervision of psychologists, medical oncologists and genetics professionals.

We recruited and trained two peer coaches to serve as trial interventionists. Both coaches are young adult relatives of *BRCA1/2* mutation carriers who have undergone our training protocol. They joined cognitive interview sessions, led by the lead study investigators, with young adult relatives to refine the manual and workbook and provided expert feedback as members of the HBOC at-risk young adult relative community. We also sought feedback on the adapted intervention from three senior board-certified cancer genetic counselors and incorporated their feedback. We further adapted approaches to include the needs of untested women by including genetic counseling resource materials in Session 1 of our protocol: <http://www.aboutgeneticcounselors.com>. This Internet site was developed by the National Society of Genetic Counselors (NSGC) and provides information about genetic counseling, genetic counselors, genetic testing, and HBOC. We also included information about HBOC community resources.

As described in Table 4, the resulting three sessions consist of (1) an orientation to the program and its purpose and establishing the purpose of a peer coach and their relationship, (2) an introduction to coping strategies, and (3) a facilitation of the health decision making process related to testing and risk management. All sessions were audiorecorded for quality assurance and reviewed by study investigators. Approximately 2 weeks after the final session ( $M = 19.9$  days,  $SD = 5.99$ , range 8–63), patients were contacted for a follow-up interview that included completion of surveys as well as cognitive interviews to refine the manual and workbook and provide expert feedback as members of the HBOC at-risk community. We additionally sought feedback about the intervention from three senior board-certified cancer genetic counselors and incorporated their feedback as well.

### Step three: intervention pilot

Table 5 includes our pilot trial results. While results for cancer-related distress and appraisals did not reach statistical significance due to low sample size, they did demonstrate changes to suggest that our intervention resulted in the changes intended. We did see a significant decrease in decisional conflict (37.3 vs. 25.7,  $p < .05$ ) as well as significant increases in many forms of healthy coping strategies, most notable planning and positive reframing ( $p$ 's  $< .01$ ). Overall, participants reported that the sessions were very helpful ( $M =$

4 out of 4), that the program met their needs related to making decisions about managing their risk ( $M = 3.7/4$ ), and that they were overall satisfied with the program ( $M = 3.8/4$ ).

## Discussion

This paper reports on the systematic adaptation of a telephone counseling intervention for young women from HBOC families. This adaptation included assessment of the population, selection of a suitable intervention, adaptation of this intervention to our target population, and piloting [29]. Our results suggest that young adult women from HBOC families have unmet cancer genetic emotional support and information needs.

Our survey results suggest that while young women generally know where to access important health information, they were only moderately satisfied with how they currently access this information, both in general and specific to their HBOC risk. Our bivariate analyses suggested that emotional distress was associated with lower levels of satisfaction with information, as well as lower levels of peer support and greater familial dysfunction and perceived cancer risk. However, in our multivariate results only familial dysfunction remained significant. This finding perhaps underscores the unique supports that family members provide in the face of familial cancer syndromes and other hereditary disease [35, 36]. When these supports are lacking, it can create greater vulnerability and need for extrafamilial support [37]. Social support provided by an informed peer who can both speak to the experience of facing heightened cancer risk and provide structured training in ways to enhance coping could mitigate distress and supplement familial relationships. This could be particularly relevant to young women who need to put their healthcare decision making into the context of their age and other developmental needs.

Our adaptation and pilot demonstrated that young women could benefit from a structured peer-led intervention that provides needed support and targets psychologic distress. While the number of participants in our pilot did not allow for significant effects across all of our outcomes, they do suggest positive effects across the outcomes of distress and decisional conflict, as well as for appraisals and coping skills. These latter variables would serve as mediators of the relationship between the women's baseline characteristics and the outcomes of distress and decisional conflict and potentially, cancer risk management variables, such as screening. The reductions in distress and decisional conflict were similar to those demonstrated in other interventions aimed at women who have received genetic testing [20, 38, 39].

This study had several limitations. The sample size for each phase of our research was relatively small and the brief amount of time allowed for our follow-up does not allow us to speak to long-term outcomes. Further, our sample was limited in its diversity in race, ethnicity and educational attainment. Future work should recruit a more diverse sample of women.

## Conclusions

Our results represent a promising peer-coach led telephone counseling intervention for young women from HBOC families. This intervention responds to the growing use of



genomic data and other biomarkers to inform precision breast cancer prevention. The number of at-risk relatives learning their family's risk for developing HBOC continues to expand. More research into effective means to support high-risk groups will maximize the benefits that testing confers to population-level outcomes. The pilot results suggest that the intervention could potentially be effective in reducing the substantial distress and decisional conflict burden in this population. Future work should test this program randomized controlled trial to test its efficacy. If proven efficacious, this model could be further disseminated through community organizations that support this population.

## Acknowledgements

This work was supported in part by Public Health Service Grant R03CA178763 (SCO) from the National Cancer Institute, a CDC Cooperative Agreement U58DP005408 (KPT and Sharsheret), and the Nontherapeutic Subject Registry and Familial Cancer Registry of Georgetown Lombardi Comprehensive Cancer Center through Comprehensive Cancer Center Support Grant P30CA051008. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health. Manuscript preparation was supported, in part, by MRSR-10-110-01 from the American Cancer Society (SCO).

## References

1. Antoniou A, Pharoah PD, Narod S et al. (2003) Average risks of breast and ovarian cancer associated with BRCA1 or BRCA2 mutations detected in case Series unselected for family history: a combined analysis of 22 studies. *Am J Hum Genet* 72(5):1117–1130. 10.1086/375033 [PubMed: 12677558]
2. Antoniou AC, Cunningham AP, Peto J et al. (2008) The BOADICEA model of genetic susceptibility to breast and ovarian cancers: updates and extensions. *Br J Cancer* 98(8):1457–1466. 10.1038/sj.bjc.6604305 [PubMed: 18349832]
3. Armstrong J, Toscano M, Kotchko N et al. (2015) Utilization and outcomes of BRCA genetic testing and counseling in a national commercially insured population: the ABOUT Study. *JAMA Oncol* 1(9):1251–1260. 10.1001/jamaoncol.2015.3048 [PubMed: 26426480]
4. Kehl KL, Shen C, Litton JK, Arun B, Giordano SH (2016) Rates of BRCA1/2 mutation testing among young survivors of breast cancer. *Breast Cancer Res Treat* 155(1):165–173. 10.1007/s10549-10015-13658-y [PubMed: 26706041]
5. Rosenberg SM, Ruddy KJ, Tamimi RM et al. (2016) BRCA1 and BRCA2 mutation testing in young women with breast cancer. *JAMA Oncol* 2(6):730–736. 10.1001/jamaoncol.2015.5941 [PubMed: 26867710]
6. Bradbury AR, Patrick-Miller L, Pawlowski K et al. (2009) Learning of your parent's BRCA mutation during adolescence or early adulthood: a study of offspring experiences. *Psycho-oncology* 18(2):200–208. 10.1002/pon.1384 [PubMed: 18702049]
7. Patenaude AF, Tung N, Ryan PD et al. (2013) Young adult daughters of BRCA1/2 positive mothers: what do they know about hereditary cancer and how much do they worry? *Psycho-oncology* 22(9):2024–2031. 10.1002/pon.3257 [PubMed: 23417902]
8. Bevers TB, Anderson BO, Bonaccio E et al. (2009) NCCN clinical practice guidelines in oncology: breast cancer screening and diagnosis. *J Natl Compr Canc Netw* 7(10):1060–1096. 10.6004/jnccn.2009.0070 [PubMed: 19930975]
9. Bosse K, Graeser M, Gossmann A, Hackenbroch M, Schmutzler RK, Rhiem K (2014) Supplemental screening ultrasound increases cancer detection yield in BRCA1 and BRCA2 mutation carriers. *Arch Gynecol Obstet* 289(3):663–670. 10.1007/s00404-00013-03022-00406 [PubMed: 24045978]
10. U.S. Preventive Services Task Force (2013) Final recommendation statement: BRCA-related cancer: risk assessment, genetic counseling, and genetic testing. <https://www.uspreventiveservice-taskforce.org/Page/Document/RecommendationStatementFinal/brca-related-cancer-risk-assessment-genetic-counseling-and-genetic-testing>. Accessed 11 July 2017

11. Bernholtz S, Laitman Y, Kaufman B, Shimon-Paluch S, Friedman E (2012) Phenocopy breast cancer rates in Israeli BRCA1 BRCA2 mutation carrier families: is the risk increased in non-carriers? *Breast Cancer Res Treat* 132(2):669–673. 10.1007/s10549-10011-11886-10543 [PubMed: 22113258]
12. Domchek SM, Gaudet MM, Stopfer JE et al. (2010) Breast cancer risks in individuals testing negative for a known family mutation in BRCA1 or BRCA2. *Breast Cancer Res Treat* 119(2):409–414. 10.1007/s10549-10009-10611-y [PubMed: 19885732]
13. Peshkin BN, Vadapampil ST, Hoskins LM, O'Neill SM, Barter JF (2015) Genetic counseling and testing for hereditary cancer risk in young adult women: facilitating autonomy and informed decision making is key. *Gynecol Oncol Rep* 14:44–45. 10.1016/j.gore.2015.10.001 [PubMed: 26793774]
14. Chen S, Parmigiani G (2007) Meta-analysis of BRCA1 and BRCA2 penetrance. *J Clin Oncol* 25(11):1329–1333. 10.1200/JCO.2006.1309.1066 [PubMed: 17416853]
15. National Comprehensive Cancer Network NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines) (2017) Genetic/familial high-risk assessment: breast and ovarian. Version 1.2018. [https://www.nccn.org/professionals/physician\\_gls/pdf/genetics\\_screening.pdf](https://www.nccn.org/professionals/physician_gls/pdf/genetics_screening.pdf). Accessed 5 Oct 2017
16. Evans C, Hamilton RJ, Tercyak KP, Peshkin BN, Rabemananjara K, Isaacs C, O'Neill SC (2016) Understanding the needs of young women regarding breast cancer risk assessment and genetic testing: convergence and divergence among patient-counselor perceptions and the promise of peer support. *Healthcare* 4(3):1–19. 10.3390/healthcare4030035 [PubMed: 27001089]
17. Hamilton RJ, Bowers BJ (2007) The theory of genetic vulnerability: a Roy model exemplar. *Nurs Sci Q* 20(3):254–264. 10.1177/0894318407303127 [PubMed: 17595406]
18. Hoskins LM, Roy KM, Greene MH (2012) Toward a new understanding of risk perception among young female BRCA1/2 “previvors”. *Fam Syst Health* 30(1):32–46. 10.1037/a0027276 [PubMed: 22429077]
19. Hoskins LM, Werner-Lin A, Greene MH (2014) In their own words: treating very young BRCA1/2 mutation-positive women with care and caution. *PLoS ONE* 9(2):e87696. 10.81371/journal.pone.0087696 [PubMed: 24586286]
20. White VM, Young MA, Farrelly A et al. (2014) Randomized controlled trial of a telephone-based peer-support program for women carrying a BRCA1 or BRCA2 mutation: impact on psychological distress. *J Clin Oncol* 32(36):4073–4080. 10.1200/JCO.2013.4054.1607 [PubMed: 25403211]
21. Graves KD, Wenzel L, Schwartz MD et al. (2010) Randomized controlled trial of a psychosocial telephone counseling intervention in BRCA1 and BRCA2 mutation carriers. *Cancer Epidemiol Biomark Prev* 19(3):648–654. 10.1158/1055-9965.EPI-1109-0548
22. Halbert CH, Wenzel L, Lerman C et al. (2004) Predictors of participation in psychosocial telephone counseling following genetic testing for BRCA1 and BRCA2 mutations. *Cancer Epidemiol Biomark Prev* 13(5):875–881
23. Perry HB, Zulliger R, Rogers MM (2014) Community health workers in low-, middle-, and high-income countries: an overview of their history, recent evolution, and current effectiveness. *Annu Rev Public Health* 35:399–421. 10.1146/annurev-publhealth-032013-182354 [PubMed: 24387091]
24. Simpson A, Flood C, Rowe J et al. (2014) Results of a pilot randomised controlled trial to measure the clinical and cost effectiveness of peer support in increasing hope and quality of life in mental health patients discharged from hospital in the UK. *BMC Psychiatry* 14:30. 10.1186/1471-1244X-1114-1130 [PubMed: 24495599]
25. Fisher EB, Coufal MM, Parada H et al. (2014) Peer support in health care and prevention: cultural, organizational, and dissemination issues. *Annu Rev Public Health* 35:363–383. 10.1146/annurev-publhealth-032013-182450 [PubMed: 24387085]
26. Dale J, Caramlau IO, Lindenmeyer A, Williams SM (2008) Peer support telephone calls for improving health. *Cochrane Database Syst Rev*. 10.1002/14651858.CD006903.pub2
27. Kenen RH, Shapiro PJ, Friedman S, Coyne JC (2007) Peer-support in coping with medical uncertainty: discussion of oophorectomy and hormone replacement therapy on a web-based message board. *Psycho-oncology* 16(8):763–771. 10.1002/pon.1152 [PubMed: 17230435]

28. Rabin C, Simpson N, Morrow K, Pinto B (2013) Intervention format and delivery preferences among young adult cancer survivors. *Int J Behav Med* 20(2):304–310. 10.1007/s12529-12012-19227-12524 [PubMed: 22328444]
29. McKleroy VS, Galbraith JS, Cummings B et al. (2006) Adapting evidence-based behavioral interventions for new settings and target populations. *AIDS Educ Prev* 18(4 Suppl A):59–73. 10.1521/aeap.2006.1518.supp.1559 [PubMed: 16987089]
30. Procidano ME, Heller K (1983) Measures of perceived social support from friends and from family: three validation studies. *Am J Community Psychol* 11(1):1–24. 10.1007/BF00898416 [PubMed: 6837532]
31. Shapinsky AC, Rapport LJ, Henderson MJ, Axelrod BN (2005) Civilian PTSD scales: relationships with trait characteristics and everyday distress. *Assessment* 12(2):220–230. 10.1177/1073191104273130 [PubMed: 15914723]
32. O'Connor AM (1995) Validation of a decisional conflict scale. *Med Decis Making* 15(1):25–30. 10.1177/0272989X9501500105 [PubMed: 7898294]
33. Carver CS (1997) You want to measure coping but your protocol's too long: consider the brief COPE. *Int. J Behav Med* 4(1):92–100. 10.1207/s15327558ijbm15320401\_15327556
34. Halbert CH, Schwartz MD, Wenzel L, Narod S, Peshkin BN, Cella D, Lerman C (2004) Predictors of cognitive appraisals following genetic testing for BRCA1 and BRCA2 mutations. *J Behav Med* 27(4):373–392. 10.1023/B:JOBM.0000042411.0000056032.0000042442 [PubMed: 15559734]
35. Giordimaina AM, Sheldon JP, Kiedrowski LA, Jayaratne TE (2015) Searching for the kinkeepers: historian gender, age, and type 2 diabetes family history. *Health Educ Behav* 42(6):736–741. 10.1177/1090198115578749 [PubMed: 25842388]
36. Koehly LM, Peters JA, Kenen R et al. (2009) Characteristics of health information gatherers, disseminators, and blockers within families at risk of hereditary cancer: implications for family health communication interventions. *Am J Public Health* 99(12):2203–2209. 10.2105/AJPH.2008.154096 [PubMed: 19833996]
37. Koehly LM (2017) It's interpersonal: family relationships, genetic risk and caregiving. *Gerontologist* 57(1):32–39. 10.1093/geront/gnw1103 [PubMed: 27507685]
38. Metcalfe KA, Dennis CL, Poll A et al. (2017) Effect of decision aid for breast cancer prevention on decisional conflict in women with a BRCA1 or BRCA2 mutation: a multisite, randomized controlled trial. *Genet Med* 19(3):330–336. 10.1038/gim.2016.1108 [PubMed: 27584910]
39. Schwartz MD, Valdimarsdottir HB, DeMarco TA et al. (2009) Randomized trial of a decision aid for BRCA1/BRCA2 mutation carriers: impact on measures of decision making and satisfaction. *Health Psychol* 28(1):11–19. 10.1037/a0013147 [PubMed: 19210013]

Table 1

## Survey participant characteristics (N = 100)

	N (%)	M (SD)	Range
Demographic characteristics			
Age		26 (3)	19–30
Education			
College student	30 (30)		
College degree	47 (47)		
Graduate studies	23 (23)		
Race			
White	75 (75)		
African American	4 (4)		
Asian American	10 (10)		
American Indian/Alaska native	1 (1)		
Other/missing	11 (11)		
Latina Ethnicity	8 (8)		
Marital status			
Married/partnered	30 (30)		
Single	70 (70)		
Annual household income			
< \$50,000	18 (18)		
\$50,000–\$100,000	24 (24)		
> \$100,000	15 (15)		
Missing	43 (43)		
Clinical characteristics			
Tested for <i>BRCA</i>	71 (71%)		
Number of cancer-affected relatives		3 (2)	1–15
Age of youngest affected relative		43 (7.4)	24–69
Psychosocial variables			
Familial disruption (brief FAM)		14.9 (4.1)	3–25
Peer support (perceived social support)		17.1 (3.2)	7–20

	N (%)	M (SD)	Range
Cancer-related distress (impact of events scale)		21.9 (14.6)	0–59
Perceived cancer risk		5.13 (1.2)	1–7
Satisfaction with information total score		29.8 (5.8)	11–40
<b>Satisfaction with information items</b>		<b>M (SD)</b>	<b>Range</b>
I know exactly what it is that I want to learn about my health in regards to <i>BRCA1/2</i>		4.0 (0.9)	1–5
At this time, I can figure out how and where to get the <i>BRCA1/2</i> information I need		3.9 (1.2)	1–5
<i>BRCA1/2</i> information is more difficult for me to obtain than other types of information. (Reverse scored)		3.4 (1.1)	1–5
I am satisfied with the way I currently learn about <i>BRCA1/2</i> issues		3.5 (0.9)	1–5
I feel that I am in control over how and what I learn about my health		4.1 (0.9)	1–5
I want <i>BRCA1/2</i> information I don't know how to get. (Reverse scored)		3.3 (1.2)	1–5
I need <i>BRCA1/2</i> information that I can't afford the time or effort to get. (Reverse scored)		3.8 (1.1)	1–5
I need <i>BRCA1/2</i> information that I can't afford to pay for. (Reverse scored)		3.9 (1.1)	1–5

**Table 2**

Bivariate associations among study variables

	Cancer-related distress	Information satisfaction	Age	Race	Partnered	Education	Tested status	No. affected relatives	Age of youngest relative	Familial dysfunction	Perceived peer support	Perceived cancer risk
Cancer-related distress	-	-0.19 <sup>+</sup>	0.08	-0.12	-0.06	0.00	-0.15	0.09	-0.08	0.30 <sup>**</sup>	-0.19 <sup>+</sup>	0.22 <sup>*</sup>
Information satisfaction		-	0.19 <sup>+</sup>	-0.06	0.18 <sup>+</sup>	0.20 <sup>*</sup>	-0.25 <sup>*</sup>	0.06	0.02	-0.26 <sup>**</sup>	0.00	-0.13
Age			-	-0.05	0.44 <sup>***</sup>	0.59 <sup>***</sup>	-0.34 <sup>***</sup>	0.06	0.02	-0.11	-0.11	0.13
Race (White vs. non-White)				-	0.13	-0.03	-0.09	-0.09	-0.09	-0.07	0.12	0.03
Partnered (Y vs. N)					-	0.29 <sup>***</sup>	-0.18 <sup>+</sup>	0.10	0.01	-0.22 <sup>*</sup>	-0.11	0.10
Education						-	-0.35 <sup>***</sup>	0.05	0.08	-0.23 <sup>*</sup>	0.07	0.06
Tested status (Y vs. N)							-	0.03	0.12	0.01	-0.02	0.01
No. affected relatives								-	-0.28 <sup>**</sup>	-0.13	-0.04	0.00
Age of youngest relative									-	0.12	0.15	-0.06
Familial dysfunction										-	-0.32 <sup>***</sup>	0.07
Perceived peer support											-	-0.09
Perceived cancer risk												-

<sup>+</sup> < .10

<sup>\*</sup> *p* < .05

<sup>\*\*</sup> *p* < .01

<sup>\*\*\*</sup> *p* < .001

**Table 3**

Multivariable regression analyses of distress

	$\beta$	SE $\beta$	Standardized $\beta$
Familial disruption	0.82	0.38	0.23*
Peer support	-0.47	0.47	-0.10
Satisfaction with information	-0.27	0.25	-0.11
Perceived cancer risk	2.17	1.21	0.17 <sup>+</sup>

<sup>+</sup> < .10\*  $p < .05$ 

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

**Table 4**

Peer coach-led intervention components

Session/goal	Description	Content/strategies
1. Orientation and psychosocial assessment: introduction, peer support, raise awareness, identify stressors	This session focuses on introducing the participant to the program, what is peer support and the peer coaching model of adjustment to HBOC risk in the family, Internet resources, and recognizing emotional/cognitive/behavioral sources of stress related to HBOC	Overview, working with a peer coach, understanding HBOC and sources of <i>BRCA</i> and HBOC stress, summarize issues, review written material
2. Coping strategy reinforcement: identify ways of coping	This session focuses on ways to enhance coping to decrease anxiety and distress, identifying healthy and unhealthy ways of coping and managing choices and common lifecycle events that are entangled with HBOC, how to untangle those events, risks/benefits of genetic counseling/genetic testing, and information needs	Reinforce written material. Definitions, examples, cognitive problem-solving training applied to genetic counseling and genetic testing for HBOC risk
3. Decision making and managing concerns: being strong for yourself	This session focuses on enhancing comprehension of risk and facilitating informed decision making, specific steps young adult relatives can take to gain information and support about HBOC, family and patient-provider communication anticipate their thoughts and feelings, and plan for next steps	Vignettes/role-playing techniques. Problem-solving, communication, decision making skills training, managing emotions, reinforce resource utilization



**Table 5**

Differences between pilot intervention target variables at baseline and follow-up (N = 10)

	<b>Baseline M (SD)</b>	<b>Follow-up M (SD)</b>	<b>p</b>
Cancer-related distress	15.8 (12.2)	12.0 (10.7)	.39
Primary appraisals	12.3 (3.6)	10.7 (3.4)	.22
Secondary appraisals	15.4 (3.4)	17.1 (2.0)	.16
Decisional conflict	37.3 (21.5)	25.7 (18.5)	.04*
Coping			
Active	2.1 (1.2)	3.1 (0.9)	.04*
Distraction	1.8 (0.9)	2.1 (1.0)	.33
Substance use	1.3 (0.7)	1.0 (0.0)	.25
Venting	1.4 (0.6)	1.9 (0.6)	.07
Instrumental	2.0 (0.8)	3.0 (0.8)	.02*
Positive reframing	1.7 (0.6)	2.7 (0.6)	.01**
Self-blame	1.2 (0.4)	1.3 (0.7)	.56
Planning	1.8 (0.9)	3.4 (0.7)	.01**
Humor	1.8 (0.8)	1.4 (0.8)	.33
Acceptance	2.5 (1.1)	3.5 (0.6)	.07
Religion	1.2 (0.4)	1.6 (0.8)	.30
Emotional support	1.1 (0.3)	1.0 (0.0)	.35
Disengagement	1.1 (0.3)	1.0 (0.0)	.35

\*  
 $p < .05$ \*\*  
 $p < .01$