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Intentions for risk-reducing surgery among high-risk women referred for BRCA1/BRCA2 genetic counseling

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Abstract

***Objective*: Genetic testing for breast and ovarian cancer susceptibility is now part of routine clinical practice. Although rates of risk-reducing surgery following genetic testing have been increasing, little is known about attitudes toward risk-reducing surgery in women prior to genetic counseling and testing. This study examines correlates of patient intentions to undergo risk-reducing mastectomy (RRM) and risk-reducing oophorectomy (RRO).**

***Methods*: Participants were 696 women, ages 21–85, who sought breast cancer gene 1 and 2 (BRCA1/2) genetic counseling and had at least a 10% risk of carrying a mutation. The sample included women who were affected with breast or ovarian cancer and unaffected women with a known familial BRCA1/2 mutation. Participants completed a precounseling telephone questionnaire.**

***Results*: Prior to receiving genetic counseling, 23.3% of participants were considering RRM and 42.5% were considering RRO. Variables that were independently associated with RRM intentions were cancer-specific distress (OR = 1.14, 95% CI = 1.03–1.26), perceived risk of breast cancer (OR = 1.16, 95% CI = 1.05–1.28), education (OR = 1.76, 95% CI = 1.03–2.99), and age (OR = 0.96, 95% CI = 0.95–0.98). Predictors of RRO intentions were perceived risk for ovarian cancer (OR = 1.25, 95% CI = 1.14–1.37), perceived risk of carrying a BRCA1/2 mutation (OR = 1.74, 95% CI = 1.15–2.62), marital status (OR = 1.92, 95% CI = 1.34–2.76), and age (OR = 1.02, 95% CI = 1.00–1.03).**

***Conclusions*: Because precounseling intentions predict subsequent risk-reducing surgery decisions, this study identified patient factors associated with surgical intentions. These factors reinforce the critical role for pretest genetic counseling in communicating accurate risk estimates and management options, and addressing psychosocial concerns, to facilitate informed decision making regarding RRM and RRO.**

Genetic counseling and testing for breast cancer gene 1 and 2 (BRCA1/2) mutations in high-risk women is now a routine part of clinical care [1]. Women who carry a BRCA1/2 mutation are at significantly increased risk for developing breast and ovarian cancer, with lifetime risks of approximately 65 and 40%, respectively [2–4]. In order to reduce their risk, many BRCA1/2 carriers consider risk-reducing mastectomy (RRM) and risk-reducing oophorectomy (RRO). RRM reduces the risk for developing breast cancer by about 90%; RRO reduces ovarian cancer risk by about 80% and when performed premenopausally also reduces breast cancer risk by 50% [5–9]. In addition, RRO is associated with reduced mortality among BRCA1/2 mutation carriers, and evidence is accumulating that RRM may also reduce mortality [10,11].

Evidence suggests that RRM and RRO intentions *prior* to genetic counseling predict risk-reducing surgery intentions and uptake following testing [12–14]. This association may be particularly strong for women who receive uninformative BRCA1/2 test results [12]. Despite the important role of precounseling preferences in subsequent medical decisions, little is known about preferences and intentions for RRM and RRO prior to genetic counseling and testing. Understanding attitudes toward RRM and RRO among women seeking genetic testing could help genetic counselors facilitate informed decisions regarding these surgeries. This is a timely question for several reasons. First, overall rates of risk-reducing surgery are rising [15–19]. Second, a substantial minority of women choose risk-reducing surgery even after receiving an uninformative negative BRCA test result [20]. Third, BRCA1/2 testing is increasingly being delivered using alternate genetic counseling approaches [21,22] or in the absence of a genetic counseling referral [23,24]. Given these trends, understanding attitudes toward risk-reducing surgery prior to genetic counseling can inform the development of targeted counseling and education designed to foster informed decision making following testing.

Although several previous studies have evaluated factors associated with RRM and RRO intentions [25–27], these studies had small sample sizes, were not focused on women who were seeking genetic counseling, and were conducted years ago when use of RRM and RRO was substantially lower than at present. The goal of this study was to examine correlates of both RRM and RRO in a large sample of women seeking genetic counseling for BRCA1/2. In selecting variables to evaluate, we were guided by prior studies and the conceptual model that guided the randomized controlled trial that was the parent study for this report. Prior research has identified demographic (e.g., age [25,28]), cognitive (e.g., perceived risk [25–27]), and affective (e.g., cancer distress [26,27]) variables associated with risk-reducing surgery intentions. We expanded on these variables by adding additional affective and cognitive variables such as perceived stress, neuroticism, quality of life, and numeracy. Further, we incorporated decisional conflict and knowledge, two key components of the Ottawa Decision Support Framework, which highlights patient decision needs that facilitate informed decision making [29,30]. Thus, in the present study, we evaluated demographic, cognitive, affective, and decision-making variables for their associations with RRM and RRO intentions prior to genetic counseling.

Methods

Participants

Participants were women who completed a baseline interview prior to enrollment in a randomized controlled trial comparing standard genetic counseling to telephone-based genetic counseling [21,22]. From 2005 to 2012, we enrolled women who were self-referred or physician-referred to the genetic counseling programs at the Lombardi Comprehensive Cancer Center (Washington, DC), Icahn School of Medicine at Mount Sinai (New York, NY), University of Vermont Cancer Center (Burlington, VT), and the Dana–Farber Cancer Institute (Boston, MA). Participants included in this report were women age 21–85 seeking BRCA1/2 genetic counseling and having at least a 10% risk for carrying a BRCA1/2 mutation [31,32]. This included women who were affected with breast or ovarian cancer and unaffected women with a known BRCA1/2 mutation in their family. We excluded individuals who had received prior cancer genetic counseling or testing, had newly diagnosed or metastatic breast or ovarian cancer, or had cognitive impairment that precluded provision of informed consent. Of 1057 eligible women, 696 (65.8%) completed a baseline interview prior to randomization for the trial. The present report includes individuals who enrolled in the clinical trial and individuals who declined or were ineligible for the trial.

Procedures

Eligible patients who referred to the clinical genetic counseling program at a study site were asked if they were interested in participating in the study. Those who agreed completed an Institutional Review Board approved verbal-informed consent procedure and a telephone interview that collected information on demographics, perceived risk, distress, decision conflict, and cancer genetic knowledge. Following the interview, the research assistant recruited and randomized willing participants to the trial. This report focuses on the baseline data collected prior to randomization.

Measures

Sociodemographics: We assessed age, race/ethnicity, marital status, education, employment, and Jewish ancestry.
Medical history: We assessed personal and family cancer history and then used these variables along with CancerGene risk software [31–33] to calculate an overall risk score (BRCAPRO probability) reflecting the a priori risk of carrying a BRCA1/2 genetic mutation. We also assessed prior or concurrent use of tamoxifen, raloxifene, and aromatase inhibitors.
Perceived risk: We measured perceived risk for breast and ovarian cancer with separate items asking participants to rate their risk on a 0 (definitely will not obtain breast cancer/ovarian cancer) to 100 (definitely will obtain breast cancer/ovarian cancer) scale. For participants who had previously been affected by breast cancer, the descriptors were 0 (definitely will not obtain breast cancer again) to 100 (definitely will obtain breast cancer again). We also measured perceived risk for carrying a BRCA1/2 mutation using a 5-point Likert style item: 'In your opinion, how likely is it that you have an altered breast–ovarian cancer gene?' We dichotomized this variable for analysis as very likely and above ($N = 184$) versus somewhat likely and below ($N = 512$).
Distress: We measured cancer-specific distress with the total score on the 15-item Impact of Event Scale [34]. Cronbach's alpha was 0.90. We measured global perceived stress with the four-item version of the Perceived Stress Scale (PSS) [35]. PSS items are rated on a 5-point Likert scale and summed for a total score. Cronbach's alpha was 0.83.
Knowledge: We measured BRCA1/2 knowledge with the 27-item Breast Cancer Genetic Counseling Knowledge Scale [36]. Total score was the number of correct responses. Cronbach's alpha was 0.82.
Numeracy: We measured numeracy with Lipkus' three-item scale [37]. The number of items answered correctly was summed to create a total numeracy score (range, 0–3). Cronbach's alpha was 0.74.
Decisional conflict: We measured decisional conflict regarding BRCA1/2 testing with the ten-item version of

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the Decisional Conflict Scale [38]. Items are scored on a weighted 3-point scale (yes (0)/unsure (2)/no (4)) with higher scores indicating greater decisional conflict. We calculated a total score by multiplying the average item score by 25. Cronbach's alpha was 0.85.

Quality of life: We measured quality of life with the SF-12 [28]. The SF-12 has two subscales, the mental component summary (MCS) and the physical component summary (PCS). Higher scores reflect better quality of life. Because of complex scoring procedures, we relied on published SF-12 internal consistency data (Cronbach's alpha, >0.82 and 0.75, for the PCS and MCS scales, respectively [39]).

Neuroticism: We measured neuroticism with the neuroticism subscale of the Neuroticism, Extraversion, and Openness Five-Factor Inventory [40]. This measure contained 12 items, with higher scores indicating higher neuroticism. Cronbach's alpha was 0.82.

Outcome variables

Surgery intentions: We assessed intentions for RRM and RRO with two face-valid items. For RRM intentions, we excluded participants who had received a prior bilateral mastectomy. Among the remaining participants, we asked whether they were considering breast surgery (yes/no), and if so, whether it was for prevention/risk reduction. Participants who were considering preventive breast surgery were classified as having intentions for RRM. We used an identical item to measure intentions for RRO (among participants who had not had a previous bilateral oophorectomy).

Analyses

We conducted separate analyses for RRM and RRO intentions. We used *t*-tests and chi-square tests to identify bivariate associations at the $p < 0.10$ level with RRM and RRO intentions. To identify variables independently associated with RRM intentions, we included all variables with a bivariate association with RRM ($p < 0.10$) in a backward logistic regression in which RRM intentions served as the dependent variable. We conducted an identical analysis for RRO intentions.

Results

Sample characteristics

Participants were predominantly non-Hispanic White (86.6%), affected with cancer (65.1%), college educated or greater (79.9%), and married (62.7%). Participants had a mean age of 47.8 years old (SD = 13.4) and a mean BRCAPRO risk score of 24.6%.

Intentions for RRM

We excluded 73 women with a prior bilateral mastectomy. Of the remaining 623 women, 145 (23.3%) reported that they were considering RRM. As displayed in Table 1, variables with significant bivariate associations with RRM intentions were the following: greater knowledge (Satterthwaite $t(277.87) = 2.91$, $p = 0.004$), higher cancer distress ($t(621) = 3.24$, $p = 0.001$), greater perceived risk for breast cancer ($t(621) = 4.36$, $p < 0.001$), greater perceived risk for ovarian cancer ($t(621) = 2.12$, $p = 0.03$), higher objective BRCA1/2 mutation risk ($t(621) = 2.30$, $p = 0.02$), no prior use of selective estrogen receptor modulators (SERMs)/aromatase inhibitors (AIs; $\chi^2(1, N = 623) = 3.78$, $p = 0.05$), non-Jewish descent ($\chi^2(1, N = 622) = 4.80$, $p = 0.03$), higher education ($\chi^2(1, N = 622) = 4.50$, $p = 0.03$), greater perceived risk of a BRCA1/2 mutation ($\chi^2(1, N = 623) = 14.30$, $p < 0.001$), no personal history of breast or ovarian cancer ($\chi^2(1, N = 623) = 7.88$, $p = 0.005$), and younger age (Satterthwaite $t(271.14) = 6.79$, $p < 0.001$).

To identify variables independently associated with RRM intentions, we included these variables in the initial step of a backward logistic regression. As displayed in Table 2, the final model revealed that the following variables were independently associated with RRM intentions: cancer-specific distress (OR = 1.14, 95% CI = 1.03–1.26), perceived risk of breast cancer (OR = 1.16, 95% CI = 1.05–1.28), education (OR = 1.76, 95% CI = 1.03–2.99), and age (OR = 0.96, 95% CI = 0.95–0.98). Women with at least a college education had a 76% greater odds of considering RRM. Each half standard deviation increase in distress and perceived breast cancer risk was associated with a 14 and 16% increased odds of considering RRM. Each 1-year increase in age was associated with a 4% decrease in the odds of considering RRM.

Intentions for RRO

We excluded 82 women who had previously had their ovaries removed. Among the remaining 614 participants, 261 (42.5%) were considering RRO. As displayed in Table 1, variables that were associated with RRO intentions at the $p < 0.10$ level were the following: greater perceived risk for ovarian cancer (Satterthwaite $t(502.73) = 5.55$, $p < 0.001$), greater perceived risk of a BRCA1/2 mutation ($\chi^2(1, N = 614) = 11.59$, $p = 0.007$), higher cancer-related distress ($t(612) = 1.86$, $p = 0.06$), being married ($\chi^2(1, N = 613) = 11.56$, $p = 0.001$), non-Hispanic White race/ethnicity ($\chi^2(1, N = 609) = 3.04$, $p = 0.08$), ovarian cancer family history ($\chi^2(1, N = 614) = 7.86$, $p = 0.005$), and age (Satterthwaite $t(594.84) = 2.04$, $p = 0.04$).

As displayed in Table 2, our final multivariate model included the following: perceived risk for ovarian cancer (OR = 1.25, 95% CI = 1.14–1.37), perceived risk of carrying a BRCA1/2 mutation (OR = 1.74, 95% CI = 1.15–2.62), marital status (OR = 1.92, 95% CI = 1.34–2.76), and age (OR = 1.02, 95% CI = 1.00–1.03). Each half standard

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Table 1. Bivariate associations between demographic, medical, cognitive, and psychosocial variables with RRM and RRO intentions

		RRM sample (*N* = 623)			RRO sample (*N* = 614)		
Variable	**Full sample (*N* = 696)**	**Intention for RRM (*N* = 145)**	**No intention for RRM (*N* = 478)**		**Intention for RRO (*N* = 261)**	**No intention for RRO (*N* = 353)**	
Continuous predictors	Mean (SD)			*p*			*p*
Age	47.8 (13.4)	41.4 (11.8)	49.3 (13.7)	<0.001	47.6 (12.1)	45.4 (13.8)	0.04
BRCAPRO probability	24.6 (22.5)	28.2 (22.7)	23.5 (21.5)	0.02	24.8 (21.1)	24.6 (22.7)	0.91
Knowledge	17.1 (4.6)	17.9 (4.0)	16.8 (4.7)	0.004	17.3 (4.4)	17.2 (4.7)	0.74
Numeracy	2.7 (0.8)	2.8 (0.7)	2.7 (0.8)	0.61	2.8 (0.7)	2.8 (0.7)	0.93
Cancer distress	21.7 (15.3)	25.2 (15.0)	20.5 (15.2)	0.001	23.3 (14.6)	21.0 (15.3)	0.06
Perceived stress	4.4 (2.5)	4.6 (2.5)	4.5 (2.6)	0.57	4.4 (2.5)	4.6 (2.5)	0.54
Physical function	50.7 (8.9)	51.2 (9.1)	50.8 (8.8)	0.62	50.9 (8.7)	51.5 (8.6)	0.43
Mental function	48.8 (10.4)	48.1 (9.9)	49.0 (10.5)	0.32	48.2 (10.9)	48.6 (10.2)	0.67
Decisional conflict	22.8 (17.8)	21.4 (17.1)	23.9 (18.2)	0.15	22.4 (17.2)	23.3 (18.5)	0.54
Neuroticism	24.6 (5.5)	24.4 (5.2)	24.8 (5.5)	0.37	24.5 (54)	24.8 (5.6)	0.48
Breast cancer perceived risk	40.8 (26.3)	51.4 (24.1)	41.1 (25.2)	<0.001	41.4 (26.8)	39.6 (25.6)	0.41
Ovarian cancer perceived risk	27.6 (22.2)	31.4 (22.4)	27.0 (22.0)	0.03	35.2 (23.3)	25.4 (19.6)	<.01
Categorical predictors	*N*, %	Intention for RRM (*N*, %)	No intention for RRM (*N*, %)	*p*	Intention for RRO (*N*, %)	No intention for RRO (*N*, %)	*p*
Education							
Less than college	140 (20.1%)	21 (16.3%)	108 (83.7%)	0.03	51 (42.9%)	68 (57.1%)	0.95
College or college+	555 (79.9%)	124 (25.2%)	369 (74.8%)		210 (42.5%)	284 (57.5%)	
Marital status							
Never or widowed	259 (37.3%)	52 (21.9%)	186 (78.1%)	0.50	79 (33.9%)	154 (66.1%)	<.01
Yes current	436 (62.7%)	93 (24.2%)	291 (75.8%)		182 (47.9%)	198 (52.1%)	
Race							
Hispanic/Non-White	92 (13.4%)	22 (27.2%)	59 (72.8%)	0.36	28 (33.7%)	55 (66.3%)	0.08
Non-Hispanic White	597 (86.6%)	121 (22.6%)	415 (77.4%)		231 (43.9%)	295 (56.1%)	
Employment							
Not employed	296 (42.6%)	61 (22.9%)	206 (77.1%)	0.81	109 (44.0 %)	139 (56.0%)	0.57
Employed current	399 (57.4%)	84 (23.7%)	271 (76.3%)		152 (41.6%)	213 (58.4%)	
Jewish descent							
No	492 (70.8%)	112 (25.8%)	323 (74.2%)	0.03	185 (42.2%)	253 (57.8%)	0.79
Yes	203 (29.2%)	33 (17.6%)	154 (82.4%)		76 (43.4%)	99 (56.6%)	
Perceived mutation risk							
Low	512 (73.6%)	89 (19.4%)	369 (80.6%)	<0.001	177 (38.6%)	282 (61.4%)	0.01
High	184 (26.4%)	56 (33.9%)	109 (66.1%)		84 (54.2%)	71 (45.8%)	
Personal breast/ovarian cancer Hx							
Unaffected	243 (34.9%)	71 (29.2%)	172 (70.8%)	0.005	97 (42.4%)	132 (57.6%)	0.95
Breast/Ovarian cancer	453 (65.1%)	74 (19.5%)	306 (80.5%)		164 (42.6%)	221 (57.4%)	
Cancer family history							
No FDR/successful detection rate (SDR)	167 (24.0%)	31 (21.2%)	115 (78.8%)	0.44	57 (38.8%)	90 (61.2%)	0.25
1 FDR/SDR breast/ovarian cancer	192 (27.6%)	46 (26.7%)	126 (73.3%)		80 (47.6%)	88 (52.4%)	
2+ SDR breast/ovarian cancer	337 (48.4%)	68 (22.3%)	237 (77.7%)		124 (41.5%)	175 (58.5%)	
Ovarian cancer family history							
No	552 (77.9%)	117 (24.5%)	361 (75.5%)	0.20	188 (39.5%)	288 (60.5%)	0.01
Yes	154 (22.1%)	28 (19.3%)	117 (80.7%)		73 (52.9%)	65 (47.1%)	
SERM/AI use							
No	502 (72.1%)	115 (25.3%)	340 (74.7%)	0.05	190 (42.1%)	261 (57.9%)	0.75
Yes	194 (27.9%)	30 (17.9%)	138 (82.1%)		71 (43.6%)	92 (56.4%)	

deviation increase in perceived risk of ovarian cancer was associated with 25% increased odds of considering RRO. Each 1-year increase in age was associated with a 2% increase in the odds of considering RRO. Married women had 92% greater odds of considering RRO than unmarried women, and women with higher perceived mutation risk had a 74% increased odds of considering RRO.

Discussion

The goal of this study was to identify variables related to pregenetic counseling intentions for risk-reducing surgery among high-risk women who had referred to a genetic counseling/testing program. Prior to genetic counseling, 23% of participants were considering RRM and 43% were considering RRO. These proportions are slightly higher

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Table 2. Backward logistic regression models of RRM and RRO

RRM				
Predictor	**Odds ratio**	**95% confidence interval**	**Chi-square**	***p*-value**
Cancer-related distress*	1.14	1.03–1.26	6.91	0.01
Perceived risk of breast cancer (high versus low)	1.16	1.05–1.28	8.16	<.01
Education (college graduate versus noncollege graduate)	1.76	1.03–2.99	4.32	0.04
Age*	0.96	0.95–0.98	25.35	<.01
RRO				
Predictor	**Odds ratio**	**95% confidence interval**		***p*-value**
Perceived risk for ovarian cancer (high versus low)	1.25	1.14–1.37	23.37	<.01
Marital status (married versus not married)	1.92	1.34–2.76	12.50	<.01
Perceived risk of a BRCA1/2 mutation (high versus low)	1.74	1.15–2.62	6.99	0.01
Age*	1.02	1.00–1.03	5.70	0.02

*The units on all continuous variables are half a standard deviation.
RRM: $N = 622$ (overall model: chi-square = 59.23, df = 4, p-value < 0.0001; model fit: -2 log L = 616.29; backward elimination removed: BRCAPRO probability ($p = 0.74$), cancer-affected status ($p = 0.88$), knowledge ($p = 0.56$), prior use of SEMs or AIs ($p = 0.82$), perceived risk of ovarian cancer ($p = 0.31$), Jewish status ($p = 0.19$), and perceived risk of a BRCA1/2 mutation ($p = 0.15$)).
RRO: $N = 609$ (overall model: chi-square = 55.94, df = 4, p-value < 0.0001; model fit: -2 log L = 774.67; backward elimination removed: race ($p = 0.28$), family history of ovarian cancer ($p = 0.21$), and cancer-related distress ($p = 0.09$)).

but generally comparable with previous studies in which 19 and 34% of participants were considering RRM and RRO, respectively [25,26]. Similarly, within the current sample, participants who enrolled later in the study (2009–2012) did not report higher precounseling intentions compared with participants who enrolled earlier in the study (2005–2008; data not shown). Despite this relative stability in precounseling surgical intentions, actual rates of risk-reducing surgery have been rising. One explanation for this seeming inconsistency can be found in studies indicating that attitudes toward risk-reducing surgery become more positive following a positive test result and that over the long-term, mutation carriers obtain RRM and RRO at higher rates than suggested by these intentions [12,20]. The combination of genetic counseling, receipt of a positive test result, and the ongoing impact of living at increased cancer risk associated likely leads some women who were not initially considering risk-reducing surgery to reevaluate this decision. Importantly, previous research also indicates that an uninformative negative test result does not lead to more negative attitudes toward risk-reducing surgery [12] and that a substantial minority of women choose to risk-reducing surgery following an uninformative negative test result [20,41]. An added focus on decision support might benefit women who enter counseling with strong intentions for risk-reducing surgery. In particular, more focus on management options following an uninformative test result could facilitate informed management decisions for this understudied group.

In this study, factors that were independently associated with RRM intentions were younger age, more years of education, higher cancer-related distress, and higher perceived risk of breast cancer. Marital status, older age, perceived mutation risk, and perceived risk for ovarian cancer were independently associated with RRO intentions.

Older age was associated with lower RRM intentions and higher RRO intentions. This difference may reflect the impact of RRO on fertility. Premenopausal women may be more likely to consider RRM because unlike ovarian cancer, the risk of breast cancer in premenopausal mutation carriers is highly elevated. Thus, younger women may view RRM as their only immediate risk reduction option. This highlights the critical role of genetic counseling in conveying alternate breast cancer risk reduction options such as premenopausal RRO or tamoxifen chemoprevention as well as breast cancer screening options.

In contrast to RRM, younger women had lower RRO intentions. The lower RRO intentions for younger women may reflect that they are less likely to have completed childbearing. Consistent with this possibility, unmarried women in our sample also had lower RRO intentions compared with married women. Apart from childbearing, premenopausal women may also prefer to avoid RRO in order to avoid surgical menopause. The higher RRO preferences of older women are consistent with guidelines for BRCA1/2 carriers that do not recommend RRO until the age of 35–40 or the completion of childbearing [1]. It is likely that RRO intentions of younger women will increase following genetic counseling as they learn that RRO prior to menopause reduces the risk for both breast and ovarian cancer. Indeed, research has demonstrated that uptake of RRO in the years following testing is substantially higher than uptake of RRM [20,42].

As in previous studies [25–27,43], cognitive and emotional factors were associated with risk-reducing surgery intentions. Perceived risk for carrying a BRCA1/2 mutation and perceived risk for ovarian cancer were associated with RRO intentions, while perceived risk for breast cancer and cancer-related distress was associated with RRM intentions. Despite a significant bivariate association with

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RRM, objective risk was not independently associated with either RRM or RRO intentions. These data are consistent with prior research indicating that uptake of risk-reducing surgery is predicted by precounseling perceived risk and distress [20,44]. Perhaps, the psychosocial factors that initially prompt patients to seek genetic testing continue to influence their decisions after the receipt of test results. Once again, these results highlight the critical role of genetic counseling in communicating accurate risk to patients prior to genetic testing. Given that intentions may be partly driven by inaccurate risk perceptions and distress and that these intentions impact subsequent decisions [12,45], genetic counseling should include explicit discussion of surgical intentions, distress, and decision making. As demand for testing increases and alternate counseling approaches become more common [22], it may become more difficult to ensure comprehensive counseling. Given this trend, the use of posttest decision support tools could help patients reach informed management decisions [46].

Despite significant bivariate associations, we did not find an independent association between having been affected with cancer and RRM or RRO intentions. This finding contrasts with research that indicates that affected BRCA1/2 mutation carriers are more likely to opt for risk-reducing surgery [20,47]. It is possible that previously-affected women underestimate their risk for developing a second cancer. Participation in genetic counseling may yield corrective changes in their perceived risk [27] that result in increased RRM and RRO intentions postcounseling. Our findings highlight the critical role of genetic counseling prior to BRCA1/2 testing, as the information conveyed in counseling likely has an important impact on how women understand the potential risks and benefits of risk-reducing surgeries.

This study had several limitations. Our sample consisted of predominantly married, well-educated, non-Hispanic White women. It is not clear that these results can be generalized beyond this population. Most of our study participants had been previously affected with cancer. Although cancer-affected status was not associated with surgical intentions in our multivariate models, additional research is needed to evaluate surgical decision making in both affected and unaffected women. Finally, our study participants had all sought genetic counseling at tertiary care centers and had provided initial consent for participation in research. Thus, their risk-reducing surgery intentions may not represent the larger population of women who seek genetic counseling and testing in the community or women who undergo testing without counseling.

Despite these limitations, our data suggest that psychosocial factors, such as cancer-related distress and perceived risk, play an important role in the surgical intentions of women seeking genetic counseling for BRCA1/2 mutations. These data underscore the need for presurgical genetic counseling and the importance of genetic counseling as a means of helping women to understand and assimilate their cancer risks and to facilitate posttest risk management decisions. However, as previous research has indicated that precounseling distress impacts risk-reducing surgery intentions and decisions [20,27,44] even after comprehensive genetic counseling, our data highlight the potential benefits of additional psychosocial and decision support, particularly for women with high levels of distress prior to counseling. Indeed, evidence suggests that anxiety can interfere with risk comprehension [48], potentially leading to poorly informed decisions. By integrating psychosocial and decision support into genetic counseling, it might be possible to ensure more fully informed management decisions. Such considerations may become increasingly important as we move away from the traditional face-to-face genetic counseling approach [22]. Future research should evaluate adjunct psychosocial and decision support interventions particularly in the context of alternate genetic counseling delivery models.

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