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## Risk Estimation, Anxiety and Breast Cancer Worry in Women at Risk for Breast Cancer: A Single-Arm Trial of Personalized Risk Communication

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### Abstract

**Objective:** Elevated anxiety and breast cancer worry can impede mammographic screening and early breast cancer detection. Genetic advances and risk models make personalized breast cancer risk assessment and communication feasible, but it is unknown whether such communication of risk affects anxiety and disease-specific worry. We studied the effect of a personalized breast cancer screening intervention on risk perception, anxiety and breast cancer worry.

**Methods:** Women with a normal mammogram but elevated risk for breast cancer (N=122) enrolled in the Athena Breast Health risk communication program were surveyed before and after receiving a letter conveying their breast cancer risk and a Breast Health Genetic Counselor

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Data Availability Statement

The data that support the findings of this study are available from the corresponding author upon reasonable request.

Conflict of interest

The authors declare no potential conflicts of interest related to the data reported in this manuscript.

consultation. We compared breast cancer risk estimation, anxiety and breast cancer worry before and after risk communication, and evaluated the relationship of anxiety and breast cancer worry to risk estimation accuracy.

**Results:** Women substantially overestimated their lifetime breast cancer risk, and risk communication somewhat mitigated this overestimation (49% pre-intervention, 42% post-intervention, 13% Gail model risk estimate,  $p < 0.001$ ). Both general anxiety and breast cancer worry declined significantly after risk communication in women with high baseline anxiety. Baseline anxiety and breast cancer worry were essentially unrelated to risk estimation accuracy, but risk communication increased alignment of worry with accuracy of risk assessment.

**Conclusions:** Personalized communication about breast cancer risk was associated with modestly improved risk estimation accuracy in women with relatively low anxiety, and less anxiety and breast cancer worry in women with higher anxiety. We detected no negative consequences of informing women about elevated breast cancer risk.

### Keywords

Anxiety; Breast Cancer Worry; Oncology; Perceived Risk; Risk Communication

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## 1. Background

One in eight women in the U.S. will be diagnosed with breast cancer over their lifetime<sup>1</sup>. Personalized risk assessment can identify women at increased risk of breast cancer and communicating that risk to patients is important to guide screening and breast cancer prevention<sup>2</sup>. It has been suggested that this individual approach could optimize disease detection and reduce over-screening<sup>3, 4</sup>.

However, communicating breast cancer risk and promulgating risk mitigation strategies to at-risk women could, in and of themselves, provoke anxiety and breast cancer worry<sup>5-7</sup>. Combined with overestimation of breast cancer risk, such an intervention might intensify psychological distress<sup>8, 9</sup>. Given the increasing opportunity to personalize breast cancer screening afforded by advances in genetics, it is critical to examine the effects of risk communication on women's perceptions of breast cancer risk, anxiety and disease-specific worry.

Breast cancer worry and general anxiety are higher among women who have a personal and family history of breast cancer<sup>10</sup>. Further, many women, including those without a family history of breast cancer, experience anxiety and worry between the mammogram procedure and receipt of a normal result<sup>8, 11</sup>. If the mammogram result is inconclusive and follow-up procedures are needed, anxiety increases<sup>12, 13</sup>. In order to implement risk feedback, we need to understand the effect of learning that one's mammogram result is normal but one's overall risk for breast cancer is elevated.

The Athena Breast Health Network<sup>14</sup> is a statewide quality improvement initiative across the University of California medical and cancer centers. It aims to assess breast cancer risk among women receiving mammograms and to provide risk-based personalized breast cancer screening. As part of Athena, this pilot study examined the relationship of personalized risk

communication in the setting of a normal mammogram result with women's breast cancer risk estimation, anxiety, and breast cancer worry.

## 2. Methods

This is a multicenter prospective pilot study conducted in University of California breast-imaging centers in Los Angeles (UCLA), San Francisco (UCSF) and San Diego (UCSD). Women were eligible if they received a mammogram and completed an Athena Breast Health screening form. Eligible women were introduced to the study at the time of their mammogram. They were told that if their mammogram result was normal, they would receive a telephone call requesting participation in the study, which would measure their anxiety related to breast cancer. Institutional review board approval was obtained at UCLA, UCSF and UCSD (#12-001516).

### 2.1 Risk Assessment and Enrollment

The Athena Breast Health screening form assessed participants' personal and family history of breast cancer. Women were classified into the breast cancer elevated risk group if either of the following criteria was met: (1) United States Preventive Services Task Force (USPSTF) guideline threshold for genetics referral for consideration of BRCA1/2 testing<sup>15</sup>, or (2) 5-year breast cancer risk score above 1.67 on the Gail model Breast Cancer Risk Assessment Tool<sup>16</sup> and in the top 5% of scores from the Gail model within their age group.

Women were contacted to participate in this study if they had a normal mammogram result (BIRAD 1–3) and were at elevated risk for breast cancer according to the above criteria. Women were excluded if they had a previous history of breast cancer, ductal carcinoma in situ, genetic testing, or previously received breast cancer risk prevention services (i.e., prescribed tamoxifen, received breast high-risk clinic consultation or had a screening breast MRI). Women were contacted via telephone call by research staff and provided oral consent to participate in the study<sup>17</sup>.

### 2.2 Breast Cancer Risk Communication

The breast cancer risk communication intervention consisted of a mailed letter followed by a telephone call from a Breast Health Genetic Counselor (BHGC). A lay language breast cancer risk letter (Supplementary material) was created by the Athena Breast Health Program and mailed to participants within two weeks of their receipt of normal mammogram results. The letter informed women of their elevated risk of breast cancer based on the information provided on the questionnaire at the time of screening. It also emphasized the need to verify the self-reported information from which the risk estimate was generated. A similar letter was sent to participants' primary care physicians to inform them of the patient's risk. During the BHGC telephone consultation, information from the risk assessment survey was validated and participants' breast cancer risk was reassessed. Concerns about breast cancer were discussed and the BHGC provided medical and psychological referrals to participants, as needed.

## 2.3 Measures

We evaluated participants' breast cancer risk estimation, anxiety, and breast cancer worry using validated questionnaires. Women were called by research staff to complete the same assessment at two time points: before receiving the risk letter (approximately 2 weeks after receiving mammogram results) and after the risk letter and BHGC consultation (6–8 weeks after receiving their mammogram result).

The baseline and follow up surveys contained the following components:

**2.3.1 Risk Estimation**—Risk estimation was assessed by two methods. First, a numerical risk estimation was generated by asking: “What do you think your chance is of developing breast cancer in your lifetime? Please choose a number between 0% (no chance of breast cancer) and 100% (definitely will get breast cancer)”<sup>18</sup>. Second, a comparative risk estimation was generated by asking “Compared to other women of the same age, do you think your chance of getting breast cancer is?” with three response options: “lower,” “the same,” and “higher.”<sup>19</sup>

**2.3.2 Anxiety**—Anxiety was assessed using the Patient-Reported Outcomes Measurement Information System (PROMIS) anxiety scale (short form 8a)<sup>20</sup>. The raw score was rescaled into a standardized T score, with higher scores indicating more anxiety. A score of 50 (standard deviation of 10) on the PROMIS 8a represents the mean score for the general population, and a score of 60 is defined as a cut-point for anxiety<sup>21, 22</sup>.

**2.3.3 Breast Cancer Worry**—Breast cancer worry was assessed using the Lerman breast cancer worry scale<sup>23, 24</sup>. The five items assessed: frequency of breast cancer worry, frequency of thinking about breast cancer, impact of breast cancer worry on mood, impact of breast cancer worry on daily activity, and self-description as “generally happy and free from worry, occasionally distressed, often distressed or extremely distressed.” For questions 1–4, responses were scored on a scale of 1 (not at all) to 4 (almost all the time). For question 5, responses were scored from 1 (generally happy and free from worry) to 4 (extremely distressed). The total breast cancer worry score ranged from 5 to 20 with a higher score indicating more worry.

## 2.4 Statistics and Data Analysis

We computed “risk accuracy” as the difference between participants' perceived risk and their lifetime breast cancer risk calculated by the Gail model<sup>16</sup>. Because women tend to overestimate their risk of breast cancer<sup>25</sup>, we categorized participants into two subgroups: accurate estimators (difference between perceived and Gail-estimated risk  $\pm 20\%$ ), and over-estimators (difference  $>20\%$ ). Concerning anxiety, for analytic purposes, participants were classified into high ( $T > 60$ ) and not-high ( $T \leq 60$ ) anxiety subgroups based on their baseline anxiety level<sup>22</sup>.

Numerical risk estimation and anxiety were summarized as mean with standard deviation. Breast cancer worry was summarized as median with interquartile range. These measures were compared between baseline and follow up using paired *t*-tests or Wilcoxon signed rank

tests, as appropriate. Pearson correlations were used to examine the correlation between numerical risk estimation, Gail model lifetime risk, anxiety, and breast cancer worry. These correlations were performed separately for each time point. Next, we used a mixed effects linear regression model to assess the relationship between anxiety and risk estimation accuracy over time. In order to account for within-participant repeated measurements, a random intercept for participant was fit along with a nested random slope for time (i.e., post vs. pre-intervention). The differential association of anxiety on risk estimation over time was examined using a time-by-risk estimate fixed effect interaction term. The association between breast cancer worry and risk estimation accuracy was examined with the same method. Two-sided p-values were reported and variables were considered statistically significant if the p-value < 0.05. Analyses were performed using STATA 15.

### 3. Results

Of 284 women with a normal mammogram result who were identified by population-based screening to be at elevated risk for breast cancer, 175 were reached by telephone to request participation, and 122 consented to participate (43% response rate). Study participants' mean age was 54.8 years, 76% were non-Hispanic white, and 95% were college graduates. (Table 1)

The median calculated Gail model lifetime breast cancer risk was 12.8%. At baseline, 16% of respondents felt that their breast cancer risk was lower, 40% about the same, and 43% higher than other women their age. After risk communication, 16% felt that their breast cancer risk was lower, 32% about the same, and 51% higher than other women their age. Women's mean numerical lifetime breast cancer risk estimate before risk communication was 49.1%, significantly higher than the mean post-risk communication risk estimate of 41.9% ( $p < 0.001$ ), and both were much higher than the Gail model risk estimate of 12.8% ( $p < 0.001$ ). The plot of numerical lifetime breast cancer risk estimate versus Gail model estimate showed that women's subjective numerical risk estimation was markedly exaggerated, widely distributed, and only moderately linked to the Gail model risk estimate at baseline ( $r = 0.29$ ,  $p = 0.001$ ) and after risk communication ( $r = 0.25$ ,  $p = 0.005$ ) (Figure 1).

Mean level of anxiety at baseline was 52.4, which was close to the population norm, and it did not change after risk communication. Breast cancer worry at baseline had a median of 7, which decreased significantly to 6 ( $p = 0.01$ ) after risk communication (Table 2a). Anxiety was more highly correlated with breast cancer worry before ( $r = 0.45$ ,  $p < 0.001$ ) than after risk communication ( $r = 0.24$ ,  $p = 0.01$ ). Breast cancer worry was not significantly correlated with risk perception at baseline ( $r = 0.06$ ,  $p = 0.53$ ), but the correlation was statistically significant after risk communication ( $r = 0.22$ ,  $p = 0.02$ ). Anxiety was not correlated significantly with risk perception at baseline ( $r = 0.02$ ,  $p = 0.83$ ) or follow-up ( $r = 0.10$ ,  $p = 0.28$ ) (Appendix Figs. 1–3).

Figures 2a and 2b demonstrate the relationship of anxiety and breast cancer worry to risk estimation accuracy, before and after risk communication. The fitted line for before and after data is derived from the mixed effects linear regression model. At baseline, the relationship between anxiety and breast cancer worry with risk estimation accuracy is nearly flat. After

risk communication, anxiety is slightly lower among those with more accurate risk estimation, although there is no statistically significant difference between the slopes of the before and after lines ( $p=0.37$ ). In contrast, the before and after risk communication lines are significantly different for breast cancer worry, with women who reported more realistic estimates of breast cancer risk having lower breast cancer worry after risk communication ( $p=0.03$ ).

In the stratified analyses of participants with high anxiety at baseline ( $N=22$ ) versus those with lower anxiety ( $N=100$ ), breast cancer risk perception decreased significantly after risk communication in the subgroup with lower anxiety (47.6% v 39.1%,  $p<0.001$ ), but not high anxiety. In the high anxiety subgroup, both anxiety (mean 63.2 vs. 59.1,  $p=0.01$ ) and breast cancer worry (median 9 v 7,  $p<0.001$ ) decreased significantly after risk communication, but neither changed in the lower anxiety subgroup (Table 2a).

In the stratified analyses based on risk estimation accuracy, mean breast cancer risk perception at baseline was 14% in the accurate estimator subgroup ( $N=34$ ) and 61% in the over-estimator subgroup ( $N=88$ ). After risk communication, nearly all women continued to overestimate their personal breast cancer risk (Figure 1 and Table 2b), although the risk perception in over-estimators decreased significantly (61.0% v 50.0%,  $p<0.001$ ). The over-estimator subgroup was more anxious than accurate-estimator subgroup at baseline (54.4 v 48.3,  $p=0.003$ ). There was no change in anxiety or breast cancer worry after risk communication in either subgroup (Table 2b).

#### 4. Discussion

Physicians, geneticists and behavioral scientists are on the brink of being able to provide personalized risk information to patients in order to guide preventive behavior<sup>26-28</sup>. It is critical to know the effect of such an intervention on patients' risk estimation accuracy, anxiety, and worry<sup>29</sup>. In the context of a single-arm personalized breast cancer risk communication trial, the present findings suggest that sending a risk letter and providing genetic counseling by telephone to inform women that they are at elevated risk of breast cancer did not provoke negative psychological responses. Building on the work of Livaudais et al., which found that risk communication did not increase breast cancer concern<sup>30</sup>, we found that risk communication combined with counseling was associated with a significant reduction in breast cancer worry among women with higher general anxiety and improved the accuracy of breast cancer risk estimation among women with lower anxiety (although substantial over-estimation persisted).

In line with previous literature<sup>8</sup>, about 20% of women in our study reported high anxiety, even after receiving a negative mammogram result, and higher anxiety was significantly associated with breast cancer worry. The finding that the correlation between anxiety and breast cancer worry was lower after risk communication compared to baseline suggests that such communication might help to de-couple general anxiety from cancer-specific worry as women's perceptions of their risk become more accurate. Such a de-coupling could help explain the seemingly paradoxical finding that communication of elevated breast cancer risk

was associated with subsequently lower breast cancer worry in the subgroup of women with higher baseline anxiety (while general anxiety was unchanged).

This study found that breast cancer risk communication reduced disease-specific worry but did not significantly decrease anxiety. This is consistent with Lerman et al's finding that risk communication could decrease breast cancer worry but not general anxiety unless the anxiety was addressed<sup>31, 32</sup>. In the context of cancer prevention, reducing high anxiety can be important because high anxiety is associated with less compliance with cancer screening and may negatively affect other health behaviors<sup>33</sup>.

Numerous studies evaluating breast cancer risk estimation reveal that women typically overestimate their risk<sup>34, 35</sup>. The present study not only demonstrates the over-estimation, but also shows that full correction of overestimation does not occur with a one-time risk communication. Others have shown that over-estimation of cancer risk is relatively resistant to change<sup>36, 37</sup>. Another study suggested that inaccurate cancer risk estimation could itself be a cause of increased anxiety and a significant predictor of breast cancer worry<sup>34</sup>; however, we found that risk estimation accuracy was only weakly correlated with anxiety and breast cancer worry. Furthermore, prior studies show inconsistency in whether genetic counseling improves risk estimation<sup>38–40</sup>. Rather than trying to correct misperceptions of risk, interventions to prevent breast cancer might focus more productively on improving screening or reducing risky behaviors.

#### 4.1 Study Limitations

The primary limitation of this study is the absence of a control group, which precludes causal inference. In addition, we used both the USPSTF guideline and Gail model for risk assessment to identify elevated-risk women, which might have led to underestimation of some women's model-based risk estimates. Furthermore, using the National Comprehensive Cancer Network guideline for risk assessment would likely identify more elevated-risk patients. In that the present sample was largely non-Hispanic white and well-educated, caution is needed when generalizing to other populations. Finally, the study was conducted over two months; later effects of risk communication are unknown.

#### 4.2 Clinical Implications

This study suggests that, at least among well-educated women, developers of personalized breast cancer risk reduction programs need not fear unintended consequences of informing women about elevated breast cancer risk.

#### 4.3 Conclusion

Personalized risk communication about breast cancer risk is associated with modest improvement in risk estimation (in women with lower anxiety) and a reduction in breast cancer worry (in anxious women). Despite communicating a message of risk, the intervention did not appear to create greater anxiety.

## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

## Acknowledgments

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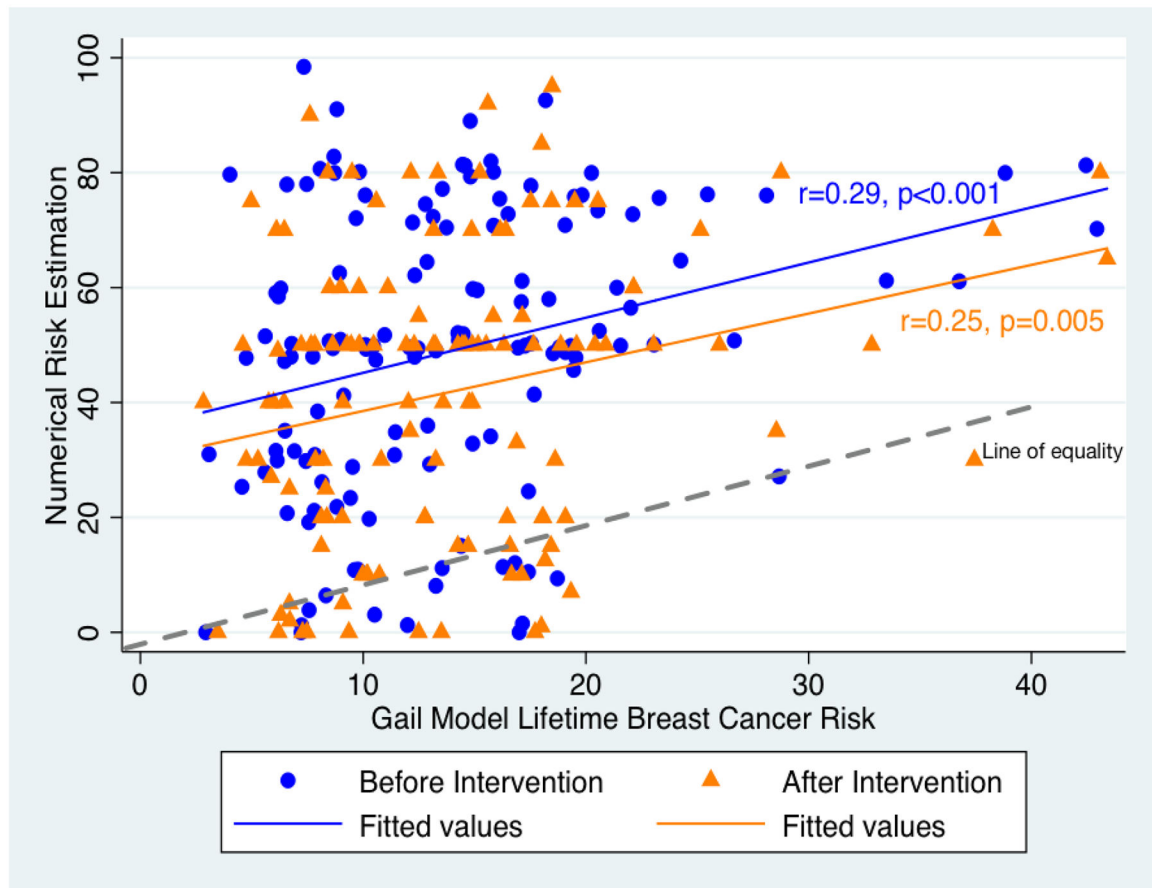
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**Figure 1.**

Plot of Women's Numerical Risk Estimate v Gail Model Lifetime Breast Cancer Risk, Before and After Risk Communication

Values on the line of equality represent accurate breast cancer risk estimations. Points above the line are overestimates and points below the line are underestimates.

Figure 2a. Anxiety and Risk Estimate Accuracy

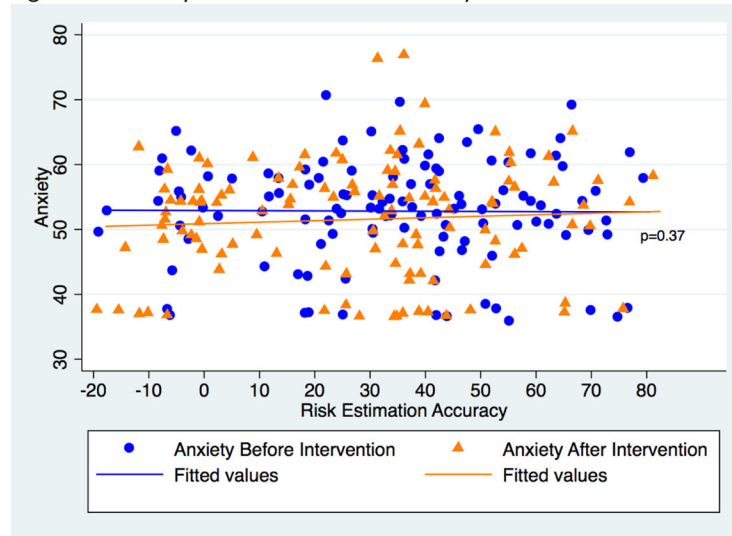
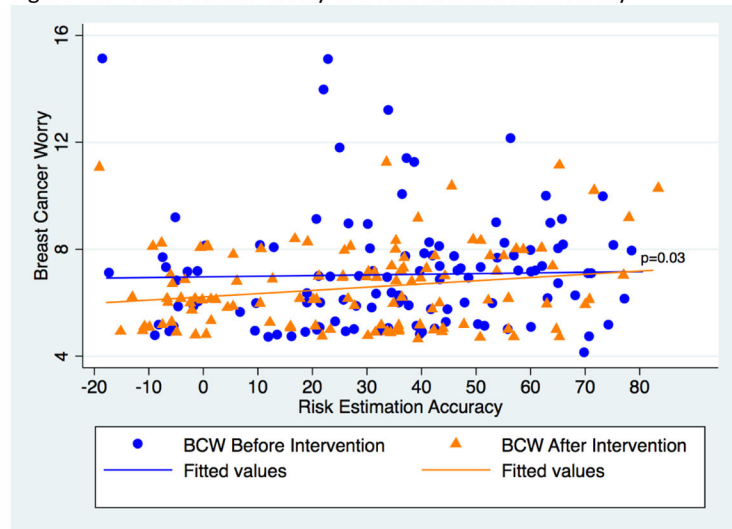


Figure 2b. Breast Cancer Worry and Risk Estimate Accuracy



**Figure 2.** Correlations between Anxiety and Breast Cancer Worry with Accuracy of Breast Cancer Risk Estimation before and after risk communication  
 Risk-estimation accuracy is Personal lifetime risk estimate minus Gail model breast cancer lifetime risk estimate.

**Table 1.**

Characteristics of Study Subjects and Gail Model Breast Cancer Risk (N=122)

<b>Age</b> , mean years (standard deviation)	54.8 (9.8)
<b>Site</b> , N (%)	
UCLA	81 (66%)
UCSF	25 (21%)
UCSD	16 (13%)
<b>Education</b> , N (%)	
Less than or graduate from high school	6 (4.8%)
Graduate from college	31 (25%)
Post-graduate degree	85 (70%)
<b>Race/Ethnicity</b> , N (%)	
Non-Latino White	93 (76%)
Latino	12 (10%)
African American	11 (9%)
Asian American	6 (5%)
<b>Breast cancer risk estimate</b> , median (Interquartile range) <sup>†</sup>	
5 year breast cancer risk	1.9% (1.3%, 3.0%)
10 year breast cancer risk	4.0% (2.7%, 5.8%)
Lifetime breast cancer risk	12.8% (8.5%, 17.7%)

<sup>†</sup>Risk estimation is based on Gail model

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**Table 2**

Comparison of Numerical Risk Estimation, Anxiety, and Breast Cancer Worry Before and After Risk Communication

<b>Table 2a Low Anxiety subgroup vs. High Anxiety subgroup (Total Sample N=122; Lower Anxiety Subgroup N=100; High Anxiety Subgroup N=22)</b>			
	<b>Before Risk Communication</b>	<b>After Risk communication</b>	<b>P value</b>
<b>Numerical Risk Estimation, mean (SD)</b>			
Overall	49.1% (24.6%)	41.9% (25.2%)	<0.001
Lower anxiety subgroup	47.6% (24.7%)	39.1% (25.0%)	<0.001
High anxiety subgroup	53.0% (24.4%)	52.5% (21.8%)	0.9
<b>Anxiety, mean (SD)</b>			
Overall	52.4 (8.2)	51.4 (8.8)	0.12
Lower anxiety subgroup	50.0 (6.9)	49.6 (8.1)	0.6
High anxiety subgroup	63.2 (3.4)	59.1 (7.3)	0.01
<b>Breast cancer worry, median (IQR)</b>			
Overall	7.0 (5–8)	6.0 (5–8)	0.01
Lower anxiety subgroup	6.0 (5,7)	6.0 (5,7)	0.3
High anxiety subgroup	9.0 (7,10)	7.0 (6,8)	<0.001
<b>Table 2b Accurate Estimate Subgroup vs. Over-estimated Subgroup. (Total Sample N=122; Accurate Estimate Subgroup N=34; Over-estimated Subgroup N=88)</b>			
	<b>Before Risk Communication</b>	<b>After Risk communication</b>	<b>P value</b>
<b>Numerical Risk Estimation, mean (SD)</b>			
Accurate estimate subgroup	14.0% (11.2%)	16.2% (13.8%)	0.46
Over-estimated subgroup	61.0% (16.1%)	50.0% (23.6%)	<0.001
<b>Anxiety, mean (SD)</b>			
Accurate estimate subgroup	48.3 (7.4)	49.0 (8.2)	0.7
Over-estimated subgroup	54.4 (7.5)	53.0 (8.9)	0.1
<b>Breast cancer worry, median (IQR)</b>			
Accurate estimate subgroup	6 (5,7)	6 (6,8)	1.0
Over-estimated subgroup	7 (6,8)	7 (5,8)	0.09

SD = standard deviation, IQR=interquartile range