Original Report:
Intersection of Social Behavior, Population Health and Inherited Traits

Accuracy of Perceived Breast Cancer Risk in Black and White Women with an Elevated Risk

Jessica M. L. Young, MS[1]; Kristen J. Vogel Postula, MS[2]; Debra Duquette, MS[1]; Melissa Gutierrez-Kapheim, MS[3]; Vivian Pan, MS[3]; Maria C. Katapodi, PhD, RN[4]

Introduction: Perceived breast cancer risk predicts screening behaviors. However, perceived risk is often inaccurate, notably in Black women, who often underestimate their risk despite having higher disease-specific mortality rates. We examined predictors of perceived breast cancer risk, and its impact on surveillance.

Methods: We used baseline data from a randomized trial targeting unaffected women recruited by relatives with early-onset breast cancer. Data collection occurred between 2012 and 2013. Accuracy of perceived risk was assessed by comparing perceived risk to objective lifetime breast cancer risks, calculated with the Gail and Claus models. A multivariate mixed model regression examined predictors of accuracy of perceived risk. The impact of perceived risk on breast cancer surveillance was assessed with one-way ANOVAS comparing Black to White women.

Results: Among participants, 21.4% self-identified as Black and 78.6% as White. Overall, 72.9% (n=247/339), 16.2% (n=55/339), and 10.9% (n=37/339) of participants overestimated, accurately perceived, and underestimated, respectively, their lifetime breast cancer risk. Race did not predict the accuracy of risk perception. Younger participants were more likely to overestimate their risk (β=-.455; CI [-.772, -.138]; P=.005). MRI utilization was predicted by a higher objective risk (F 1,263 [= 30.271]; P<.001) and more accurate risk perception (P=.010; Fisher's exact test).

Conclusions: Most women with a family history of early-onset breast cancer inaccurately perceived their risk for developing the disease. Younger women were more likely to overestimate their risk. Findings can guide the development of tailored interventions to improve adherence to breast cancer surveillance recommendations. *Ethn Dis*. 2022; 32(2):81-90; doi:10.18865/ed.32.2.81

Keywords: Early-onset Breast Cancer; Family History; Health Disparities; Surveillance

[1] Northwestern University, Chicago, IL
[2] GeneDx, Gaithersburg, MD
[3] University of Illinois Cancer Center, Chicago, IL
[4] University of Basel, Switzerland

Address correspondence to Maria Katapodi, University of Basel, Department of Clinical Research, Basel, Switzerland. maria.katapodi@unibas.ch

Background and Significance

Breast cancer is the most commonly diagnosed female cancer, affecting one in eight women in the United States, and is the second leading cause of cancer-related death.[1] In recent decades, breakthroughs in epidemiology, molecular biology, and genetics have improved our understanding of the etiology of the disease. Early detection through breast cancer surveillance protocols have helped decrease morbidity and mortality.[2] Breast cancer risk assessment tools, such as the Gail[3] and Claus[4] models, help health care providers assess an individual's risk to develop the disease based on epidemiologic variables, and reproductive and family history. These tools can be used to tailor recommendations about breast cancer screening and to determine candidates for genetic evaluation. However, the benefits of these advancements have not been experienced equally; while Black women have a lower lifetime incidence of breast cancer compared to White women (126.7 vs 130.8 per 100,000), they experience higher mortality rates (28.4 vs 20.3 deaths per 100,000),[1] significantly contributing to the growing disparity in mortality rates between Black and White women in the United States.[5] This disparity is especially profound in women aged <50 years, where Black women experience mortality rates 1.9-2.6 fold higher than White women.[1]

About 18% of breast cancers are early-onset, diagnosed in women aged <50 years.[1] Black women are more likely than White women to be diagnosed before the age of 50 (23% compared to <16%, respectively).[1] Early-onset breast cancer is suggestive of a possible genetic predisposition[6] and confers a 2- to 5.7-fold elevation in breast cancer risk for blood relatives

depending on factors such as degree of relationship and age at diagnosis.[7,8] However, some women with a family history of early-onset breast cancer may not be aware that having a relative diagnosed at a young age confers a significant increase in their own risk. This misunderstanding may lead to inaccurate perceptions of breast cancer risk, which could inhibit women from adopting appropriate screening behaviors. High-risk women who underestimate their risk may miss important opportunities for screening, early detection, and chemoprevention. Conversely, women who overestimate their risk may suffer unnecessary anxiety.[9]

The purpose of this study was to examine the accuracy of perceived breast cancer risk among Black and White women with a family history of early-onset of the disease…

According to the Theory of Planned Behavior (TPB), intentions and behaviors are functions of individuals' attitudes (eg, perceptions of risk), perceived behavioral control, and subjective norms (eg motivation to comply with recommendations from healthcare providers).[10,11] Higher perceived breast cancer risk has been associated with adherence to recommendations for breast self-examination,[12] mammography,[13] and chemoprevention.[14] Thus, the accuracy of perceived risk is important, as individuals at the extreme ends of the spectrum either do not screen as frequently as recommended,[15] or overuse screening modalities.[9] Having an accurate perception of risk is especially important for Black women, who are less likely than White women to know that their own risk for developing the disease increases after a breast cancer diagnosis in a first-degree relative.[16]

The purpose of this study was to examine the accuracy of perceived breast cancer risk among Black and White women with a family history of early-onset of the disease, and whether inaccurate perceptions of risk influence screening behavior. The specific aims were to compare perceived breast cancer risk to an objective risk estimate among unaffected women with family history of early-onset breast cancer; compare the accuracy of perceived risk between Black and White women; explore predictors of accurate risk perceptions; and explore whether accuracy of perceived risk predicts breast cancer screening behaviors (clinical breast exam, mammography, and breast MRI).

Methods

Design, Subjects, and Procedures

This is a secondary analysis of baseline data from a randomized trial that tested the efficacy of two interventions designed to increase surveillance and use of genetics services for women with early-onset breast cancer and their unaffected female relatives (ClinicalTrial.gov ID: NCT01612338). IRB approval for the original study was obtained from the University of Michigan, the Michigan Department of Health and Human Services, and the Scientific Advisory Board of the Michigan Cancer Surveillance. This analysis also received IRB approval from Northwestern University. All procedures were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000. Informed consent was obtained from all participants.

Methodological details have been published elsewhere.[11] In short, enrolled women with early-onset breast cancer were asked to invite their female relatives to the study. Only relatives that breast cancer patients were willing to contact were recruited. Two genetic counselors used a pedigree-based algorithm to determine candidate relatives, giving priority to younger and first-degree relatives. Relatives were eligible to participate if they self-identified as female and were between 25-64 years old, unaffected by cancer, living in the United States, English-speaking, able to provide consent, and a first- or second-degree relative of the breast cancer patient. Excluded were relatives who were pregnant, institutionalized, or incarcerated at the time of the study. Participating patients received a letter suggesting up to two eligible relatives to invite to the study, in order to have comparable family units. If relatives did not respond within eight weeks the research team contacted the patient asking if she could contact an alternate relative. Completed

questionnaires from relatives were reviewed by two genetic counselors to determine eligibility. Data collection occurred between 2012 and 2013. The baseline questionnaire took approximately 45 minutes to complete. Participants received $10.

Measures

Perceived breast cancer risk was assessed using a number line, ranging from 0% to 100%. An accompanying narrative and visual anchors explained that the risk of breast cancer for most women is 12% compared to a small subset with a pathogenic genetic variant who have a 50%-80% risk. The narrative also explained that "nobody" has either a 0% or 100% risk. Participants provided a value of believed percent risk.

Objective lifetime risk estimates were calculated with the Gail[3] and Claus[4] models. The Breast Cancer Risk Assessment Tool (BCRAT; https://bcrisktool.cancer.gov/) was used to calculate lifetime risks based on the Gail model. When a Gail risk estimate was not available, due to age or missing data, the Claus risk estimate was used for analysis. When both risk estimates were available, the higher of the two was used. This decision was based on clinical genetic counseling practices, as the higher of the two risks is often used to guide clinical management decisions for genetic testing and high-risk breast cancer surveillance.

Accuracy of risk perception was assessed in two ways. First, the magnitude of difference between perceived and objective lifetime breast cancer risk, or the total percentage inaccuracy, was calculated by subtracting the objective from the perceived risk score. Second, the accuracy of perceived risk was assessed categorically to represent below average or average risk (<12%), slightly increased risk (13%-19%), moderate risk (20%-49%), and high-risk (>50%). These cutoffs represent clinically meaningful categories signaling changes in managing breast cancer risk.[17] Contrasting the perceived risk category with the objective risk category created four accuracy categories: accurate (perceived risk was in the same category as objective risk);underestimate (perceived risk was in a lower category than objective risk); moderately overestimate (perceived risk was one category higher than objective risk); and grossly overestimate (perceived risk was two or more categories higher than objective risk).

Screening behaviors were assessed with six questions, two for each modality (clinical breast exam [CBE], mammogram, and breast MRI). Participants were given a brief description of each modality and were asked whether they had ever been screened in that manner. Those who answered yes were then asked how often they received screening through that modality in the previous 12 months. CBE and mammogram adherence were defined using the National Comprehensive Cancer Network (NCCN) guidelines that were in effect at the time of the study, which recommended annual CBE for women aged ≥25 years, and annual mammograms starting at age 40 for woman with breast cancer risk <20%, or age 35 for those with a ≥20% lifetime risk.[18] MRI utilization was defined as having received at least one breast MRI prior to the study. Participants who were aged <35 years were excluded from breast MRI analyses.

Participants were asked to rank *"how much control do you feel you have over your chances of getting breast cancer"* with a 7-point Likert scale ranging from *"not at all"* to *"a lot"*. Self-efficacy scores were calculated as the average of four self-efficacy questions (confidence to ask for a CBE, mammogram, breast MRI, and genetic testing). Two measures of family support – average family support and average family support in illness – were used. The average family support variable was a composite score of 15 questions assessing how supported participants felt by their family. The average family support in illness variable took the average score of 10 questions that assessed participants' familial support in times of illness. All questions were scored on a 7-point Likert scale with 1 being negative and 7 being positive. All measures were dichotomized or collapsed into positive/negative/neutral responses for analyses.

The questionnaire also assessed demographic characteristics, participants' family history of cancer, and whether participants or their families had undergone genetic testing or utilized cancer genetics services.

Statistical Analyses

Data analysis was performed with SPSS version 27.[19] P<.05 was considered statistically significant for all analyses. The first aim was addressed with frequencies to describe categorical data; means, ranges, and standard deviations were used for continuous data. Differences between Black and White participants were assessed with one-way analysis of variances (ANOVAs), Chi-squared tests, and Fisher's exact tests. The second aim was addressed with a linear regression

with a mixed model approach to identify predictors of accurate risk perception while accounting for dyads in the sample, as some relatives were invited by the same breast cancer survivor.

As fixed effects, we entered demographic variables (age, race, marital status), socioeconomic variables (income, education, insurance status, recent inability to access health care due to cost), psychosocial variables (previous diagnosis of depression or anxiety), and Theory of Planned Behavior-related variables:[10] experience with genetic testing either personally or through family members; confidence to ask a health care provider for a CBE or mammogram and genetic testing or a breast MRI; beliefs that relatives and health care providers encourage participation in breast cancer screening; family support; and family support in illness). A family unit variable was created to account for the family dyads and was entered as the random effect.

The third aim was addressed with one-way ANOVAs to examine the impact of participants' perceived risk, objective risk, and the accuracy of risk perception (total percentage inaccuracy and accuracy of clinical categorization) on breast cancer surveillance.

Results

Among the 853 relatives who were invited to participate in this study, n=431 (50.5%) accepted participation. Participants who identified as non-Black minorities (n=13) or did not provide their race (n=12) were excluded from this study. The final study population consisted of 87 (21.4%) Black and 319 (78.6%) White unaffected women with a family history of early-onset breast cancer. Characteristics of the sample are shown in Table 1. Participants' mean age was 43.4±12.0 years and did not differ significantly between Black (44.9 ± 11.3) and White (42.9±12.1) participants. Black participants reported lower income (P<.001) and lower education (P<.001) and were less likely to be employed (61.0% vs 75.4%; P=.009) compared to White participants. Black participants were less likely to be insured than White participants (75.9% compared to 89.3%; P=.001), and more often reported cost-related barriers to accessing care (28.6% compared to 17.4%; P=.022). Overall, 56.2% were members of dyad family units, which did not significantly differ by race (P=.834).

Black women had a lower objective breast cancer risk than White women (14.4±6.8% vs 18.8±7.6%; F(1,367)=20.089; P<.001), and reported a lower perceived breast cancer risk than White women (32.8±21.5% vs 39.8±22.2%; F(1,368)=5.797; P=.017). Regardless of race, women perceived their breast cancer risk to be approximately double their objective risk (Figure 1).

Despite breast cancer risk falling along a continuum, approximately one in three participants (29.2%; n=108/370) perceived their breast cancer risk to be 50%. This group had an average objective breast cancer risk of 19.2±7.7% and overestimated their risk by 30.8±7.7%. These participants were primarily White (81.5%; n=88/108), married or in long-term partnerships, employed, and insured, with a mean age of 43.0±11.8 years. The majority did not have a college degree, had not received genetic services or undergone genetic testing and reported that they had no or little control over their chances to develop cancer. Interestingly, 10 individuals reported that they had a 0% lifetime breast cancer risk. The mean objective risk for this group was 13.7±6.0%. These participants were primarily Black (80%; n=8/10), not employed, had lower income and educational attainment, and a mean age of 49.7±13.8 years. Most of these respondents reported feeling some or a lot of control over their chances of developing cancer.

Most participants over-estimated their breast cancer risk, regardless of race. The mean difference between perceived and objective risk was 20.1±21.1% overestimation, ranging from -29.3% to 81%. Only 16.2% (n=55/339) had an accurate risk perception, while 10.9% (n=37/339) underestimated their risk; 33.9% (n=115/339) moderately overestimated their risk; and 38.9% (n=132/339) grossly overestimated their risk. Participants' race did not significantly affect the accuracy of clinical management categorization (P=.720) or the total percentage inaccuracy (P=.647).

A mixed-model multiple linear regression examined predictors of breast cancer risk perception inaccuracy. Age was the only variable that significantly predicted total percentage inaccuracy, with younger participants being more likely to overestimate their risk (β=-.455; CI [-.772, -.138]; P=.005; Table 2).

Race did not significantly impact breast cancer surveillance with CBE, mammography, or breast MRI. Overall, 76.4% (n=310/393) and 70.0% (n=184/255) of wom-

Table 1. Demographic characteristics of the study participants, N=406

Characteristic	Total population, N=406	Black, n=87	White, n=319	P
Number of relatives with breast cancer				
One	223 (58.1)	49 (62.8)	174 (56.9)	
More than one	161 (41.9)	29 (37.2)	132 (43.1)	.341
Income				
<$39,000	127 (34.9)	39 (53.4)	88 (30.2)	
$40,000-$79,000	113 (31.0)	25 (34.2)	88 (30.2)	
>$80,000	124 (34.1)	9 (12.3)	115 (39.5)	<.001[e]
Marital status				
Single	164 (40.5)	58 (66.7)	106 (33.3)	
Married/life partner	241 (59.5)	29 (33.3)	212 (66.7)	<.001[e]
Employment				
Employed	283 (72.4)	50 (61.0)	233 (75.4)	
Not employed	108 (27.6)	32 (39.0)	76 (24.6)	.009[e]
Education				
College degree or more	184 (46.1)	23 (28.0)	161 (50.8)	
No college degree	215 (53.9)	59 (72.0)	156 (49.2)	<.001[e]
Insurance status				
Has insurance	351 (86.5)	66 (75.9)	285 (89.3)	
No insurance	55 (13.5)	21 (24.1)	34 (10.7)	.001[e]
Issues with access due to cost[a]				
Yes	79 (19.7)	24 (28.6)	55 (17.4)	
No	322 (80.3)	60 (71.4)	262 (82.6)	.022[f]
Accuracy of risk categorization[b]				
Accurate	55 (16.2)	11 (18.3)	44 (15.8)	
Underestimated	37 (10.9)	5 (8.3)	32 (11.5)	
Moderately overestimated	115 (33.9)	18 (30.0)	97 (34.8)	
Grossly overestimated	132 (38.9)	26 (43.3)	106 (38.0)	.720
Perceived control regarding cancer				
No or little control	243 (61.5)	42 (53.2)	201 (63.6)	
Neutral	61 (15.4)	14 (17.7)	47 (14.9)	
Some or a lot of control	91 (23.0)	23 (29.1)	68 (21.5)	.219
Age, Mean ± SD	43.4 ± 12.0	44.9 ± 11.3	42.9 ± 12.1	.170
Objective lifetime breast cancer risk[c], Mean ± SD	17.9 ± 7.6	14.4 ± 6.8	18.8 ± 7.6	<.001[e]
Perceived lifetime breast cancer risk, Mean ± SD	38.4 ± 22.2	32.8 ± 21.5	39.8 ± 22.2	.017[f]
Total percentage inaccuracy of perceived risk[d], Mean ± SD	20.1 ± 21.1	19.0 ± 21.8	20.4 ± 21.0	.647

All values expressed as n(%) with valid percentages shown to account for missing values unless otherwise noted.
a. Participants were asked if there was a time in the last 12 months where they needed to see a doctor but could not due to cost
b. Measure of the difference in clinical management categorization of perceived and objective risk
c.Objective risk represents participants' Gail or Claus lifetime risk, or the higher of the two for participants where both are available
d. Measure of the discrepancy between perceived and objective risk
e. P<.01; f. P<.05)

en reported having clinical breast exam (CBE) and mammography as recommended, respectively. However, neither risk perception, objective risk, nor total percentage inaccuracy of risk perception predicted breast cancer surveillance through CBE or mammography (Table 3).

Participants with a higher objective breast cancer risk were more likely to have had a breast MRI in the past (M=25.7±9.8% vs 17.5±6.9% for those who did not; P<.001). MRI utilization was associated with risk categorization accuracy, as those who did not report having an MRI were more likely to grossly overestimate their risk (34.2%; n=75/219). No association was found with breast MRI history and perceived risk or total percentage inaccuracy. Only

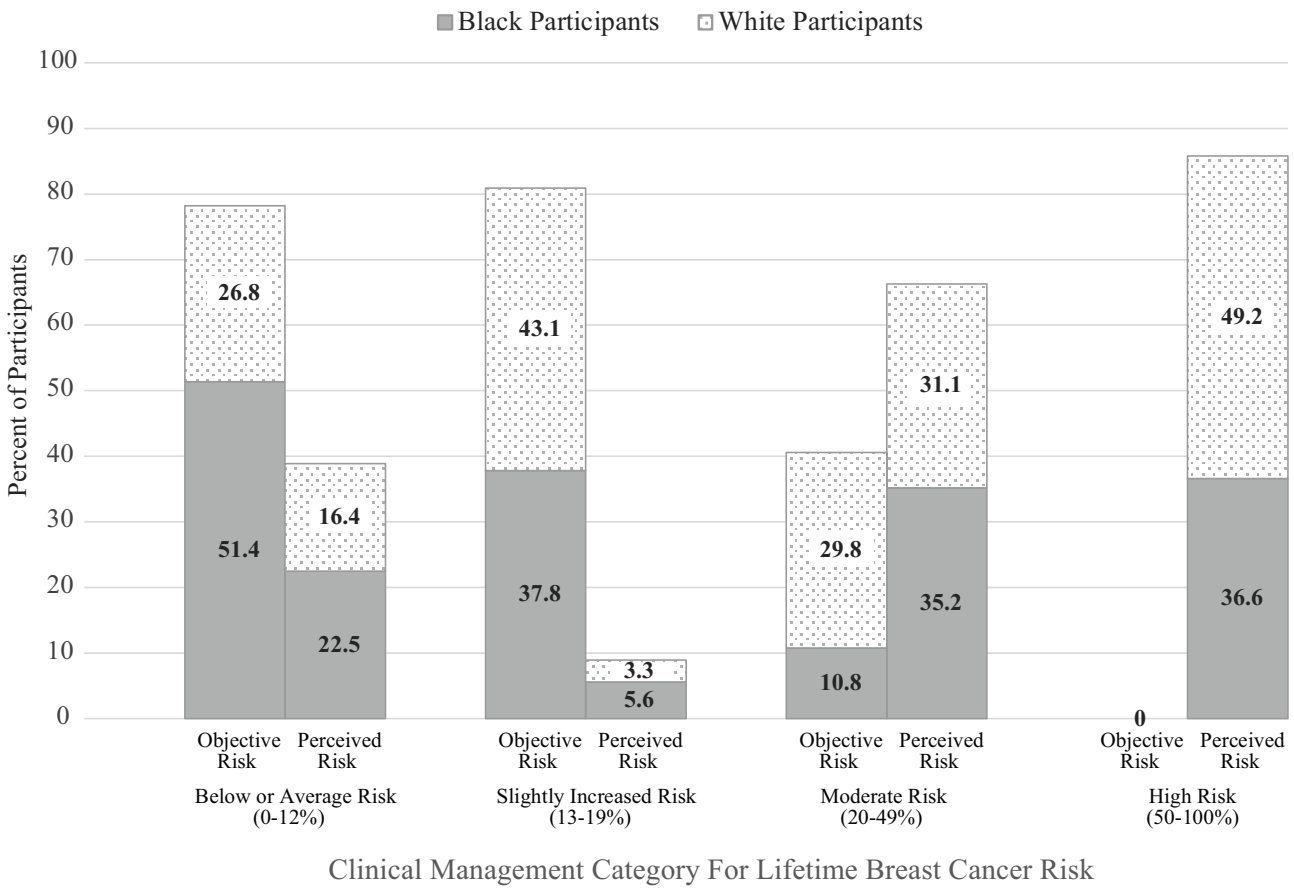

Figure 1. Participants' perceived and objective lifetime breast cancer risks, N=406

22.1% (n=17/76) of participants who met breast MRI criteria reported having had at least one breast MRI.

Discussion

This study compared the accuracy of perceived breast cancer risk for Black and White women with a family history of early-onset disease, and examined the impact of risk perception accuracy on screening behaviors. A considerable number of participants misunderstood their breast cancer risk, with the vast majority overestimating it. However, the most frequent response, 50%, may represent the opinion that one will "get [cancer] if you're going to get it," as noted previously among women at increased risk for the disease.[20] In our study most participants felt "no control" or "little control" over their chance to develop breast cancer. Perceived control has been shown to impact both risk perception and decision-making about preventive health behaviors.[21] While perceived control was not a significant predictor of participants' total percentage inaccuracy, those who reported less control over developing breast cancer were more likely to overestimate their risk according to clinical management cut-offs. Other possible explanations of this finding may lay in the recruitment methodology and the measurement item. Individuals recruited through an affected relative may be more aware of the disease and, in turn, overestimate their risk.[22] Moreover, questions that assess perceived risk from 0%-100% are more likely to produce an overestimation,[22] since adults with low health literacy have a harder time interpreting percentages.[23,24]

Accuracy of risk perception was

not associated with race, irrespective of the way accuracy was assessed. This contradicts previous reports indicating that Black women have less accurate perceptions of their breast cancer risk. Previous studies have shown that Black women are more likely to perceive their risk to be lower than the average woman, and have hypothesized that this is due to perceptions in the Black community that breast cancer is a "White woman's disease."[25] Alternatively, studies have shown Black women to be unrealistically pessimistic about their risk, possibly because they face higher mortality rates.[26] Income and education are significant confounders of the association between race and perceived risk, as previous studies reported that women with lower income and educational attainment are more likely to overestimate their risk.[26] In this study, Black women were more likely to have a lower income and less education, thus, the lack of a significant association of these factors on the accuracy of risk perception is surprising. The lack of

Table 2. Mixed-model multiple linear regression of the factors influencing the accuracy of risk perception in Black and White women with a family history of early-onset breast cancer, N=406

	b	SE
Objective risk	-.020	(.222)
Age	-.455[k]	(.161)[k]
Average CBE/mammogram self-efficacy	-.792	(1.720)
Average breast MRI/genetic testing self-efficacy	-1.133	(1.212)
Perceived expectations for breast cancer surveillance from relatives	4.774	(6.463)
Perceived expectations for breast cancer surveillance from providers	-1.782	(3.623)
Average family support	.502	(2.208)
Average family support in illness	-.462	(2.475)
White[a]	-.487	(5.458)
Annual income >$80,000[b]	2.162	(5.342)
Annual income $40,000-$79,000[b]	5.106	(4.479)
Partnered[c]	-1.326	(3.953)
Employed[d]	-.850	(4.036)
Has a bachelor's degree or higher[e]	-3.043	(3.770)
Insured[f]	-3.561	(5.956)
No issue accessing healthcare due to cost[g]	3.008	(5.659)
Family member has had genetic testing[h]	-2.382	(3.565)
Depression[i]	.984	(4.632)
Anxiety[j]	-3.311	(4.385)

a. ref=Black
b. ref=annual income <$39,999
c. ref=non-partnered
d. ref=not currently employed
e. ref=no college degree
f. ref=uninsured
g. ref=issues accessing healthcare due to cost
h. ref=no family members had genetic testing
i. ref=not diagnosed with depression
j. ref=not diagnosed with anxiety
k. Of statistical significance (P<.05)

Table 3. Women's use of clinical breast exam and mammography by their objective risk, risk perception, and accuracy of risk perception, N=406

	Clinical breast exam (CBE)			Mammogram		
	Utilize	Do not utilize	P	Utilize	Do not utilize	P
Objective lifetime breast cancer risk[a]	17.8 ± 7.3	18.3 ± 8.5	.676	18.6 ± 7.7	18.9 ± 8.4	.845
Perceived lifetime breast cancer risk	38.3 ± 21.9	39.5 ± 23.9	.514	34.7 ± 22.0	38.8 ± 23.3	.212
Total percentage inaccuracy of perceived breast cancer risk[b]	20.3 ± 20.8	20.8 ± 22.5	.844	15.6 ± 20.8	20.0 ± 22.5	.161
Accuracy of risk categorization, %(n) [c]						
Accurate	15.1 (39)	18.3 (13)		19.3 (32)	13.8 (9)	
Underestimated	11.2 (29)	9.9 (7)		18.1 (30)	10.8 (7)	
Moderately overestimated	34.5 (89)	29.6 (21)		37.3 (62)	33.8 (22)	
Grossly overestimated	39.1 (101)	44.3 (30)	.803	25.3 (42)	41.5 (27)	.085

All data presented as mean±SD unless otherwise noted.
a, Objective risk represents participants' Gail or Claus lifetime risk, or the higher of the two for participants where both were available
b. Measure of the discrepancy between perceived and objective risk
c. Measure of the difference in clinical management categorization of perceived compared to objective risk

difference between Black and White participants perceived risk, and the lack of significant predictors of an accurate risk may be attributed to the fact that all were recruited through a breast cancer survivor, thus, they had similar experiences with the disease.

Younger participants were more likely to grossly overestimate their breast cancer risk compared to older ones. The negative association of age with perceived risk has been previously reported.[16,27] It is possible that older women with previous history of negative mammograms or other negative screening history, have a false sense of security or the idea that one may have outlived their breast cancer risk.[20] Thus, younger women may be an overlooked group that needs additional counseling to improve accuracy of perceived risk, which may help improve screening according to national recommendations.

In our study most participants felt "no control" or "little control" over their chance to develop breast cancer.

Studies regarding the impact of risk perception and its accuracy on breast cancer screening have mixed findings. Some studies reported no impact of risk perception on breast cancer screening (BSE, CBE, mammography)[28] while others reported that a higher perceived risk predicted mammography[25] and breast MRI[29] screening. In our study, neither measure of accuracy was associated with mammography utilization. Only 22% of participants who met breast MRI criteria reported having received such screening at the time of the study, which is consistent with previous findings.[30] Although breast MRI recommendations were not new in 2012-2013, insurance companies were less likely to cover this cost, physicians may not have been aware of the surveillance guidelines, and breast MRI machines were not commonly available. Despite these barriers, our findings support a significant association between accuracy of perceived risk and MRI surveillance. Since breast MRIs are currently more widely accessible, the assessment of breast cancer risk perception and MRI use should be repeated in a similar high-risk population.

We did not find a significant relationship between CBE or mammography utilization and perceived risk, objective risk, accurate categorization of risk, or total percentage inaccuracy. Although most participants inaccurately perceived their breast cancer risk, most reported using CBE and mammography according to NCCN guidelines,[18] irrespective of race. Interestingly, participants who grossly overestimated their risk were more likely to be younger and less likely to have had an MRI. Possible explanations for this finding include lack of referrals because health care providers did not recognize that their family history qualifies them for MRI screening, or lack of insurance coverage for MRI screening due to their young age. These factors, in turn, could be associated with exaggerated perceptions of risk. These findings are important to consider in the development of tailored interventions to increase the accuracy of risk perception and breast cancer surveillance for women with family history of early-onset disease.

Study Limitations

The intent of the RCT was to evaluate interventions designed to increase awareness of breast cancer risk and surveillance for women with a family history of early-onset breast cancer. The study design and the sampling strategy intentionally recruited younger and primarily first-degree relatives of early-onset breast cancer patients, who were most likely to benefit from these interventions. Additionally, screening behaviors were self-reported, which may have introduced a bias as prior studies have found significant discordance between self-reported screening behavior and screening data from medical charts[31] and follow-up survey data.[15] This effect has been found to be more pronounced in Black women, and is thought to be due to a "telescoping effect" where women recall receiving screening more recently than is the case.[31] Physician behavior has been found to be an important predictor of CBE and mammography,[32] and was not assessed in this study.

Conclusions

Women with family history of early-onset breast cancer benefit from

informed decision making regarding their breast cancer surveillance options, such as breast MRI surveillance in addition to CBE and mammography, initiating screening at an earlier age or at more frequent intervals, and breast cancer chemoprevention. While many women with family history of early-onset breast cancer utilized NCCN guidelines as recommendations for CBE and mammograms, public health initiatives to increase identification of women who qualify for breast MRIs and/or chemoprevention are also important. Efforts to improve accuracy of percieved risk may increase adherence to underutilized high-risk screening protocols, especially for high-risk Black women as we continue to address known disparities in detection and treatment. In this new era of precision medicine, there is an urgent need for more innovative and personalized communication methods and interventions to 'precisely' provide to specific populations and individuals.

Acknowledgements

This study was supported by the Centers for Disease Control and Prevention (CDC), 5U48DP001901-03, and by the Robert Wood Johnson Foundation (RWJF)—Nurse Faculty Scholars 68039 Award to M.C.K. The authors would like to acknowledge Jenna McLosky, MS, CGC for participant recruitment, evaluation of eligibility, and risk calculations, and Kari Mendelsohn-Victor, MPH for participant recruitment. The authors would also like to acknowledge Beth Anderson, MPH for her work on this manuscript, statistical expertise, and supervision.

Conflict of Interest

No conflicts of interest to report.

Author Contributions

Research concept and design: Young, Postula, Pan, Duquette, Katapodi; Acquisition of data: Duquette, Katapodi; Data analysis and interpretation: Young, Gutierrez-Kapheim, Katapodi; Manuscript draft: Young, Postula, Gutierrez-Kapheim, Pan, Duquette, Katapodi; Statistical expertise: Gutierrez-Kapheim; Acquisition of funding: Katapodi; Administrative: Katapodi; Supervision: Postula, Gutierrez-Kapheim, Pan, Duquette, Katapodi

References

1. DeSantis CE, Ma J, Gaudet MM, et al. Breast cancer statistics, 2019. *CA Cancer J Clin*. 2019;69(6):438-451. https://doi.org/10.3322/caac.21583 PMID:31577379
2. Myers ER, Moorman P, Gierisch JM, et al. Benefits and harms of breast cancer screening: A systematic review. *JAMA*. 2015;314(15):1615-1634. https://doi.org/10.1001/jama.2015.13183 PMID:26501537
3. Gail MH, Costantino JP. Validating and improving models for projecting the absolute risk of breast cancer. *J Natl Cancer Inst*. 2001;93(5):334-335. https://doi.org/10.1093/jnci/93.5.334 PMID:11238688
4. Claus EB, Risch N, Thompson WD. Autosomal dominant inheritance of early-onset breast cancer. Implications for risk prediction. *Cancer*. 1994;73(3):643-651. https://doi.org/10.1002/1097-0142(19940201)73:33.0.CO;2-5 PMID:8299086
5. O'Keefe EB, Meltzer JP, Bethea TN. Health disparities and cancer: racial disparities in cancer mortality in the United States, 2000-2010. *Front Public Health*. 2015;3(51):51. https://doi.org/10.3389/fpubh.2015.00051 PMID:25932459
6. Kleibl Z, Kristensen VN. Women at high risk of breast cancer: molecular characteristics, clinical presentation and management. *Breast*. 2016;28:136-144. https://doi.org/10.1016/j.breast.2016.05.006 PMID:27318168
7. Collaborative Group on Hormonal Factors in Breast Cancer. Familial breast cancer: collaborative reanalysis of individual data from 52 epidemiological studies including 58,209 women with breast cancer and 101,986 women without the disease. *Lancet*. 2001;358(9291):1389-1399. https://doi.org/10.1016/S0140-6736(01)06524-2 PMID:11705483
8. Pharoah PD, Day NE, Duffy S, Easton DF, Ponder BA. Family history and the risk of breast cancer: a systematic review and meta-analysis. *Int J Cancer*. 1997;71(5):800-809. https://doi.org/10.1002/(SICI)1097-0215(19970529)71:53.0.CO;2-B PMID:9180149
9. Halbert CH, Kessler L, Wileyto EP, et al. Breast cancer screening behaviors among African American women with a strong family history of breast cancer. *Prev Med*. 2006;43(5):385-388. https://doi.org/10.1016/j.ypmed.2006.06.003 PMID:16860380
10. Ajzen I. The theory of planned behavior. *Organ Behav Hum Decis Process*. 1991;50(2):179-211. https://doi.org/10.1016/0749-5978(91)90020-T
11. Katapodi MC, Northouse LL, Schafenacker AM et al. Using a state cancer registry to recruit young breast cancer survivors and high-risk relatives: protocol of a randomized trial testing the efficacy of a targeted versus tailored intervention to increase breast cancer screening. *BMC Cancer*. 2013;13:97. https://doi.org/10.1186/1471-2407-13-97
12. Cohen M. First-degree relatives of breast-cancer patients: cognitive perceptions, coping, and adherence to breast self-examination. *Behav Med*. 2002;28(1):15-22. https://doi.org/10.1080/08964280209596394 PMID:12244641
13. Laing SS, Makambi K. Predicting regular breast cancer screening in African-American women with a family history of breast cancer. *J Natl Med Assoc*. 2008;100(11):1309-1317. https://doi.org/10.1016/S0027-9684(15)31510-8 PMID:19024228
14. Bober SL, Hoke LA, Duda RB, Regan MM, Tung NM. Decision-making about tamoxifen in women at high risk for breast cancer: clinical and psychological factors. *J Clin Oncol*. 2004;22(24):4951-4957. https://doi.org/10.1200/JCO.2004.05.192 PMID:15598980
15. Calvocoressi L, Kasl SV, Lee CH, Stolar M, Claus EB, Jones BA. A prospective study of perceived susceptibility to breast cancer and nonadherence to mammography screening guidelines in African American and White women ages 40 to 79 years. *Cancer Epidemiol Biomarkers Prev*. 2004;13(12):2096-2105. PMID:15598767
16. Hughes C, Lerman C, Lustbader E. Ethnic differences in risk perception among women at increased risk for breast cancer. *Breast Cancer Res Treat*. 1996;40(1):25-35. https://doi.org/10.1007/BF01806000 PMID:8888150
17. Liu Y, Pérez M, Aft RL, et al. Accuracy of perceived risk of recurrence among patients with early-stage breast cancer. *Cancer Epidemiol Biomarkers Prev*. 2010;19(3):675-680. https://doi.org/10.1158/1055-9965.EPI-09-1051 PMID:20160274
18. National Comprehensive Cancer Network: NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines TM): Breast Cancer Screening and Diagnosis Version 1.2011 2011. Last accessed February 20, 2022 from https://www.nccn.org/guidelines/guidelines-detail?category=2&id=1503
19. IBM Corp. IBM SPSS Statistics for Windows, Version 27.0. Armonk, NY: IBM Corp. Released 2020.
20. Anderson EE, Tejada S, Warnecke RB,

Hoskins K. Views of low-income women of color at increased risk for breast cancer. *Narrat Inq Bioeth*. 2018;8(1):53-66. https://doi.org/10.1353/nib.2018.0023 PMID:29657180
21. Gunn CM, Bokhour BG, Parker VA, et al. Understanding decision-making about breast cancer prevention in action: The intersection of perceived risk, perceived control, and social context: NRG Oncology/NSABP DMP-1. *Med Decis Making*. 2019;39(3):217-227. https://doi.org/10.1177/0272989X19827258 PMID:30803311
22. Katapodi MC, Lee KA, Facione NC, Dodd MJ. Predictors of perceived breast cancer risk and the relation between perceived risk and breast cancer screening: a meta-analytic review. *Prev Med*. 2004;38:388-402. https://doi.org/10.1016/j.ypmed.2003.11.012
23. Rutherford EJ, Kelly J, Lehane EA, et al. Health literacy and the perception of risk in a breast cancer family history clinic. *Surgeon*. 2018;16(2):82-88. https://doi.org/10.1016/j.surge.2016.06.003 PMID:27908542
24. Speiser D, Rebitschek FG, Feufel MA, Brand H, Besch L, Kendel F. Accuracy in risk understanding among *BRCA1/2*-mutation carriers. *Patient Educ Couns*. 2019;102(10):1925-1931. https://doi.org/10.1016/j.pec.2019.05.007 PMID:31079956
25. Orom H, Kiviniemi MT, Shavers VL, Ross L, Underwood W III. Perceived risk for breast cancer and its relationship to mammography in Blacks, Hispanics, and Whites. *J Behav Med*. 2013;36(5):466-476. https://doi.org/10.1007/s10865-012-9443-z PMID:22772713
26. Waters EA, Klein WM, Moser RP, et al. Correlates of unrealistic risk beliefs in a nationally representative sample. *J Behav Med*. 2011;34(3):225-235. https://doi.org/10.1007/s10865-010-9303-7 PMID:21110077
27. Fehniger J, Livaudais-Toman J, Karliner L, et al. Perceived versus objective breast cancer risk in diverse women. *J Womens Health (Larchmt)*. 2014;23(5):420-427. https://doi.org/10.1089/jwh.2013.4516 PMID:24372085
28. Katapodi MC, Dodd MJ, Lee KA, Facione NC. Underestimation of breast cancer risk: Influence on screening behavior. *Oncol Nurs Forum*. 2009;36(3):306-314. https://doi.org/10.1188/09.ONF.306-314
29. Killelea BK, Lannin DR, Horvath LJ, Horowitz NR, Chagpar AB. Factors associated with breast MRI use: a population-based analysis. *Ann Surg Oncol*. 2013;20(6):1798-1805. https://doi.org/10.1245/s10434-012-2758-8 PMID:23208129
30. Wernli KJ, DeMartini WB, Ichikawa L, et al; Breast Cancer Surveillance Consortium. Patterns of breast magnetic resonance imaging use in community practice. *JAMA Intern Med*. 2014;174(1):125-132. https://doi.org/10.1001/jamainternmed.2013.11963 PMID:24247555
31. McPhee SJ, Nguyen TT, Shema SJ, et al. Validation of recall of breast and cervical cancer screening by women in an ethnically diverse population. *Prev Med*. 2002;35(5):463-473. https://doi.org/10.1006/pmed.2002.1096 PMID:12431895
32. Orji CC, Kanu C, Adelodun AI, Brown CM. Factors that influence mammography use for breast cancer screening among African American women. *J Natl Med Assoc*. 2020;112(6):578-592. https://doi.org/10.1016/j.jnma.2020.05.004 PMID:32641257