Impact of Implementing B-RST™ to Screen for Hereditary Breast and Ovarian Cancer on Risk Perception and Genetic Counseling Uptake Among Women in an Academic Safety Net Hospital

Karen Wernke,[1] Cecelia Bellcross,[1] Sheryl Gabram,[2,3,4] Nadia Ali,[1] Christine Stanislaw[1,4]

Abstract

This study measures change in risk perception following use of the Breast Cancer Genetics Referral Screening Tool (B-RST™). Risk perception for 126 women was assessed prior to and immediately after administration of B-RST™. B-RST™ has a significant impact on cancer risk perception and, consequently, the level of interest in genetic counseling. Low appointment adherence shows a need to further assess barriers to genetic counseling.

Background: Lower socioeconomic status is strongly associated with decreased perception of cancer risk. Fewer low socioeconomic status women than expected currently access cancer genetic services from which they may benefit. **Patients and Methods:** We screened women presenting for a screening mammogram at a safety net academic hospital using the Breast Cancer Genetics Referral Screening Tool Version 3.0 (B-RST™), an online tool designed to identify individuals potentially at risk for hereditary breast and ovarian cancer. Participants screening either positive (high risk) or negative (moderate risk) were offered genetic counseling appointments. We used a brief survey to evaluate change in risk perception before and after using B-RST™, and after a genetic counseling appointment, if applicable. Barriers to accepting appointments were assessed when participants declined. **Results:** Of the 126 participants, 91 (72.2%) screened negative-average risk, 13 (10.3%) screened negative-moderate risk, and 22 (17.5%) screened positive. Of those who screened positive or negative-moderate, 24 (68.6%) expressed interested in a genetic counseling appointment, of which 19 (79.2%) scheduled. Four of the 19 scheduled (21.1%) completed the appointment. We found a significant difference in the number who rated their breast cancer risk correctly on the post-test between the groups who self-rated as low, moderate, or high risk. Those who perceived themselves as high risk were the most likely to rate their risk correctly on the post-test ($P < .001$). **Conclusion:** We showed that using B-RST™ in a safety net academic hospital was effective at identifying women at increased risk for hereditary breast and ovarian cancer.

Clinical Breast Cancer, Vol. 19, No. 4, e547-55
Keywords: BRCA1, BRCA2, Risk assessment, Risk model, Socioeconomic status

Introduction

Hereditary breast and ovarian cancer (HBOC) is caused by pathogenic mutations in the *BRCA1* or *BRCA2* genes. It is estimated that 1 of 300 to 1 of 500 individuals in the general population carry a mutation in *BRCA1* or *BRCA2*.[1] A mutation in a BRCA gene confers a lifetime breast cancer risk of 50% to 80%, as well as a lifetime ovarian cancer risk of 10% to 40%.[2,3] Identifying individuals with these mutations has the potential to decrease

Present Address: K.W., TriHealth Cancer Institute, Bethesda North Hospital, Cincinnati, OH

[1]Department of Human Genetics
[2]Department of Surgery, Emory University School of Medicine, Atlanta, GA
[3]AVON Comprehensive Breast Center at Grady Memorial Hospital, Atlanta, GA
[4]Winship Cancer Institute of Emory University, Atlanta, GA

Submitted: Nov 12, 2018; Revised: Feb 9, 2019; Accepted: Feb 27, 2019; Epub: Mar 11, 2019

Address for correspondence: Karen Wernke, MMSc, LCGC, TriHealth Cancer Institute, Bethesda North Hospital, 10494 Montgomery Rd, 2nd Floor, Cincinnati, OH 45242
E-mail contact: karen_wernke@trihealth.com

1526-8209/$ - see frontmatter
https://doi.org/10.1016/j.clbc.2019.02.014

incidence of breast and ovarian cancers, and thereby lessen the morbidity and mortality associated with these diagnoses. The incidence of breast and ovarian cancers may be decreased if risk reduction modalities of care are offered to mutation carriers.[4-6]

The Breast Cancer Genetics Referral Screening Tool (B-RST™) is an online tool (https://brcagenescreen.org/) that was designed and validated to identify individuals potentially at risk for HBOC.[7-9] The United States Preventative Services Task Force recommends the utilization of screening tools, including B-RST™, by healthcare providers to identify women who may benefit from genetic counseling regarding their HBOC risk.[1,10] The revised algorithm B-RST™ 3.0 was found to have 94% sensitivity to identify individuals with a *BRCA1/2* mutation, while maintaining specificity significantly higher than that of the National Comprehensive Cancer Network Guidelines, Version 1.2018.[9,11]

Recent studies indicate that women in lower socioeconomic populations access screening services less than is recommended by standard guidelines.[12-14] Of the high-risk, lower socioeconomic status (SES) women who have access to screening services, only an estimated 25% receive the genetic counseling for which they are referred.[15] The various barriers to accepting and following through with a genetic counseling appointment need to be further investigated. Pagan et al showed that breast cancer screening among these lower SES populations is strongly associated with adequate health literacy, which might impact risk perception.[15] It is well-documented that 2 consistent predictors of genetic counseling uptake include greater perceived risk of developing cancer and having a personal and/or family history of cancer.[16] Assessing risk perception and reasons individuals decline genetic counseling might provide insight for improving follow-up with mammography.

The purpose of this study was to measure change in risk perception following use of B-RST™ and to assess barriers to attending genetic counseling appointments. We screened women presenting for a screening mammogram at a safety net academic hospital using B-RST™. The majority of the patients that are seen in the breast imaging center of this safety net hospital are underinsured and have a low SES. We assessed change in perception of cancer risk following use of B-RST™. We hypothesized that using B-RST™ would increase the accuracy of cancer risk perception in our participants. Additionally, we offered free genetic counseling services to women found to be at high risk of HBOC in hopes of reducing barriers to genetic counseling. We further assessed barriers via survey as patients declined genetic counseling appointments.

Patients and Methods

Population

All English-speaking female patients with an appointment for a screening mammogram at the Avon Comprehensive Breast Center at Grady Memorial Hospital were eligible to participate in the study. The Grady Health System, one of the largest public health systems in the United States, provides care for underserved populations mainly from Fulton and DeKalb counties in Georgia. In 2014, 23.5% and 19.6% of adults under 65 years of age living in DeKalb and Fulton counties, respectively, were uninsured.[17] Additionally, approximately 19% of adults in both counties were on Medicaid.[17] Recruitment lasted from July 2017 to October 2017, during which an estimated 1169 women were seen for a screening mammogram.

Study Design and Procedures

The study was a quantitative, prospective, experimental feasibility study. The study had approval from the Emory University Institutional Review Board as well as the Grady Research Oversight Committee. The authors declare that they have no conflict of interest.

After completing a screening mammogram, potential participants were informed about the study by the study coordinator or mammogram technicians. Interested patients were consented, and basic demographic characteristics were collected, including age, race, type of insurance, and number of daughters. Number of daughters was ascertained as a potential factor influencing risk perception. Participants were then provided with an initial paper-based survey.

This survey consisted of 5 brief questions aimed at assessing risk perception and knowledge of cancer risk (Table 1). The study coordinator administered the B-RST™ 3.0 screen using a tablet. This screening tool collected annual household income and education level, prior to collecting family and/or personal history of breast and ovarian cancer. Participants were informed that the screening tool estimated their risk for having a hereditary predisposition to breast cancer using information about their family history. After the screen, B-RST™ 3.0 results were explained to each participant, and a short post-test was administered. The same questions on the pre-test were asked on the post-test, with the exception of "what brings you in for a screening mammogram today," which was replaced with "how surprised are you by your risk assessment result?" (Table 1). A screen of positive was explained as an increased chance to have HBOC and thus a good candidate for genetic counseling and testing. These women were told that if they do have HBOC, they are much more likely than the average woman to develop breast or ovarian cancer. For these participants, genetic counseling was recommended. Participants screening negative-

Table 1 Pre-test/Post-test Survey

Question	Possible Responses
Pre-Test (1) What brings you in for a screening mammogram today?	• It's suggested for finding cancer early • My doctor told me to get one • A family member told me to get one • I noticed something on/in my breast • I am at risk for breast cancer and/or someone in my family has had breast cancer
Post-Test (1) How surprised are you by your risk assessment result?	• Not surprised • A little surprised • Surprised • More surprised • Surprised a lot
(2) How concerned are you about getting breast cancer?	• Not worried • A little worried • Worried • More worried • Worried a lot
(3) How would you rate your overall risk of getting breast cancer?	• Average • A little higher than average • A lot higher than average
(4) How would you rate your risk of getting breast cancer compared to other women?	• The same • Higher • Much higher
(5) What things do you believe impact your risk for breast cancer?	• Open-ended

moderate risk were informed that they were unlikely to carry a *BRCA* gene mutation, but had a modest increased risk for breast cancer based on family history. Those screening negative-moderate were informed that their family history may make their risk for breast cancer greater than that of the average woman. Because of this potential risk, genetic counseling was offered to more precisely assess risk for hereditary cancer. Those screening negative-average risk were told they were not expected to be at increased risk for HBOC based on their family history and thus genetic counseling was not recommended. Each individual was given a handout that described their risk result and provided resources for more information.

Study participants who screened either positive or negative-moderate were offered a free genetic counseling appointment to discuss their personal risk of breast cancer in more detail. Those who accepted and completed an appointment were again given the post-test survey to determine further risk perception changes. With grant funding from the organization It's the Journey, Inc. for the program at Grady entitled 'Bridging the Gap: Genetic Access Program for Individuals at Risk for Hereditary Breast Cancer,' access to counseling and genetic testing was provided at no cost to individuals. Participants who declined an appointment or scheduled a genetic counseling appointment and did not show up, were asked "What is/are the main reason(s) that you do not want to speak to a genetic counselor?" Choices were: fear they will not protect my information, fear they will use the information to discriminate against me, no time for appointment, fear of unknown, fear of having positive results, don't want testing, transportation is difficult for extra appointments, don't think it is important, and other. A maximum of 3 contact attempts were made before participants were considered lost-to-follow-up.

Analysis

All analysis was done using IBM SPSS Statistics Data Editor version 24. The χ^2 and Fisher exact tests were used to determine significance of changes in cancer risk perception from pre-test to post-test, as well as between post-test and true B-RST^{TM} score. Significance of risk perception change accuracy was determined via χ^2 analysis between groups of those who did or did not change in risk perception, and whether they self-rated their risk correctly on the post-test. Independent *t* tests were performed to test for significant changes in level of concern to develop breast cancer between the screening groups. Power calculations based on anticipated change in self-rater breast cancer risk (pre/post screening), beta of 0.20 and alpha of 0.05, yielded a target of 126 participants.

Results

Participant Characteristics

Figure 1 illustrates the number of subjects participating in each step of the process. The total enrollment number for the study was 126 women who completed B-RST^{TM}. An average of 36 patients were seen for a screening mammogram each day, with an average of 4 participants per recruitment day. Individuals were informed about the study either by the study coordinator directly or by the mammogram technicians. If the patient was informed by a mammogram technician and was interested in participating, the patient was brought to the study coordinator after completing her screening mammogram. If they were informed about the study, but chose not to participate, they left after their mammogram without talking to the study coordinator. The mammogram technicians did not keep track of who was informed about the study. For these reasons, the exact participation rate was not able to be calculated.

Of the 126 participants, the majority (91.3%) were African American. The average age of the entire study population was 56.7 years, with a range from 32 to 82 years. A majority (61.1%) of the study population reported an annual household income of $25,000 or less, with 42.1% reporting $15,000 or less. Nearly equal numbers of individuals had a high school education (33.3%) or some college (32.5%). The highest proportion of individuals were uninsured (42.9%) or on Medicare/Medicaid (42.1%) (Table 2).

When asked the pretest question "what brings you in for a screening mammogram today?" most participants (57.9%) responded "my doctor told me to get one." The second most selected response (25.4%) was "it's suggested for finding cancer early."

Screen Results

Of the 126 women screened with B-RST^{TM}, 91 (72.2%) screened at negative-average risk, 12 (9.5%) screened negative-moderate risk, and 23 (18.3%) screened positive risk. Overall, 81 (64.8%) of the participants noted on the post-test that they were not surprised by their screening results. Of those who screened positive, 11 (47.8%) were not surprised. Among those who screened negative-average and negative-moderate, 63 (70.0%) and 7 (58.3%) were not surprised, respectively.

Concern About Breast Cancer

Among all participants, 81.2% and 86.5% indicated not worried or a little worried on the pre-test and post-test, respectively. Among the negative-average screens, there was a significant decrease in level of worry from pre-test to post-test ($P = .025$). Those who screened positive were significantly more likely to have a higher level of worry on the post-test than those in the negative-average group ($P < .001$) and those in the negative-moderate group ($P = .015$).

Perceived Risk Factors

On both the pre-test and post-test questionnaires, we asked, "What things do you believe impact your risk for breast cancer?" in an open response format. Among those who gave answers (n = 77; 61.1%), the most common response on both the pre- and post-tests was "family history" (22.2% and 24.6% on pre- and post-tests, respectively). The second most popular response was "smoking cigarettes," which was answered by 19 (15.1%) participants on both surveys, followed by "diet," with 15 (11.9%) and 17 (13.5%) providing this answer on the pre- and post-tests.

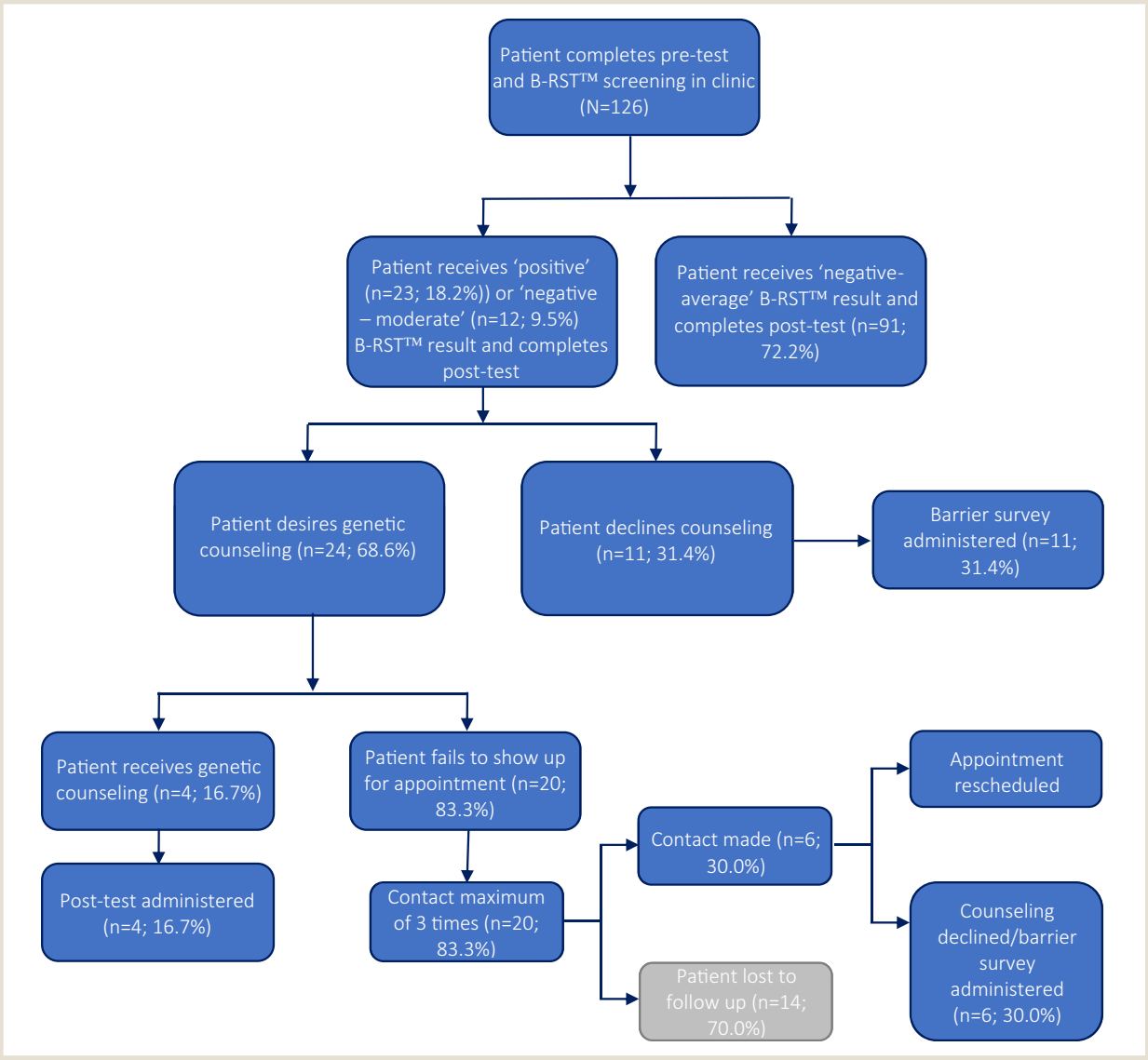
Change in Risk Perception

Of those who first perceived themselves as average risk, 3 (3.3%) increased in risk perception from pre-test to post-test. Of the self-perceived a little higher than average and a lot higher than average groups, 11 (44.0%) of 25 and 5 (55.6%) of 9, respectively, changed their perception from pre-test to post-test. Those who initially perceived themselves as average risk were significantly less likely to perceive their risk differently on the post-test ($P < .001$).

Risk Perception Accuracy

When compared with B-RST^{TM} scores, participants who perceived their risk as average at baseline were most likely to be correct

Figure 1 Flow Chart of Study Procedure and Number of Participants at Each Step



Abbreviation: B-RST™ = Breast Cancer Genetics Referral Screening Tool.

(n = 72; 80%) (Table 3). When compared with B-RST™, 65.3% rated their risk correctly on the pre-test, whereas 67.7% rated their risk correctly on the post-test, which was not a significant increase ($P = .606$). There was a significant difference in the number of participants who rated their risk correctly on the post-test between the groups who self-rated their risk as average, a little higher than average, or a lot higher than average (Table 4). Those who perceived themselves as high risk on the post-test were the most likely to rate their risk correctly (4/5; 80.0%) as compared with those who perceived themselves in other risk groups ($P < .001$).

On the pre-test, 19 (15.3%) women overestimated their risk, which decreased to 11 (8.9%) on the post-test. However, more women underestimated their risk on the post-test (29; 23.4%) when compared with the pre-test (24; 19.4%). On the post-test, the majority of women screening negative-moderate (11; 91.7%) and positive (18; 81.8%) underestimated their risk. Most women screening negative-average did not overestimate their risk on the pre- (72; 80.0%) or post-test (79; 87.8%). Figure 2 demonstrates the change in risk-perception from pre-test to post-test within each of the screen groups.

To combine change in risk perception with accuracy of post-test risk perception, we compared those who changed with those who did not and assessed if their post-test rating matched their B-RST™ score. Those with a correct baseline risk perception (n = 105) were significantly less likely to change in cancer risk perception ($P = .039$). Of those who did change in risk perception (n = 19), 9 changed to the correct perception. All 9 participants that correctly changed their risk perception had overestimated their risk on the pre-test. The majority of participants who did not change in risk perception were correct in their initial rating (75/105; 71.1%).

Table 2 Demographic Information

Characteristic	n (%)
Race	
African American	115 (91.3)
Caucasian	6 (4.8)
Hispanic	5 (4.0)
Age, y	
30-39	3 (2.4)
40-49	19 (15.1)
50-59	58 (46.0)
60-69	33 (26.2)
70-79	12 (9.5)
80-89	1 (0.8)
Income	
$15,000 or less	53 (42.1)
$15,001-$25,000	24 (19.0)
$25,001-$50,000	19 (15.1)
$50,001-$75,000	3 (2.4)
$75,001 or more	2 (1.6)
I do not wish to answer	25 (19.8)
Education	
Less than high school	19 (15.1)
Grade 12 or GED	42 (33.3)
Some college	41 (32.5)
College graduate (4 years)	12 (9.5)
Graduate or professional degree	8 (6.3)
I do not wish to answer	4 (3.2)
Insurance status	
Medicare/Medicaid	53 (42.1)
Exchange	7 (5.6)
Private	12 (9.5)
None	54 (42.9)
Number of daughters	
0	38 (30.2)
1	55 (43.7)
2	21 (16.7)
3	9 (7.1)
4	3 (2.4)

Abbreviation: GED = General Educational Development.

Appointment Data

Of the 23 women that screened at positive risk and 12 women that screened at negative-moderate risk on B-RST™, 24 (68.6%) were interested in being seen for genetic counseling. Among the 24 participants interested in genetic counseling, 19 (79.2) had screening positive. Twenty (83.3%) women scheduled a genetic counseling appointment, of whom 16 (80.0%) had screened positive. However, only 4 (20.0%) out of the 20 women attended their appointment. Three (75.0%) of those who attended an appointment were positive screens. One of the participants who did not attend later completed a genetic counseling appointment as a result of a diagnosis of breast cancer on the mammogram.

Barriers

We had 17 participants complete the barrier survey. The top reason for declining a genetic counseling appointment was that participants did not have time for an appointment (n = 7; 41.1%). The second most given response what that participants did not think that having a genetic counseling appointment was important (n = 4; 23.5%).

Discussion

Our study demonstrated a need for genetic counseling services among underinsured women at this safety net hospital, with 23 (18.3%) of participants screening at increased risk for HBOC. In a 2010 study using B-RST™ 2.0, Bellcross et al demonstrated a screen positive rate of 6.2%, with 70.5% of the population screening negative-moderate.[8] A later study by Bellcross et al comparing B-RST™ 2.0 with B-RST™ 3.0 found an increase in the number of women screening positive and a decrease in those screening negative-moderate, which would yield results closer to numbers reported here.[9] However, although 19 (82.6%) of the screen-positive women in our study indicated interest in a genetic counseling appointment, only 3 (16.6%) attended their appointment. Additionally, we found that using B-RST™ to screen family history and explaining the screen results to patients had a significant impact on cancer risk perception. We hypothesized that using B-RST™ would increase risk perception accuracy. More participants perceived their risk correctly on the post-test compared with the pre-test. We found a significant improvement in risk perception accuracy from pre-test to post-test between the groups who self-rated their risk as average, a little higher than average, or a lot higher than average.

Similar to our findings, several other interventions have been shown to adjust women's perception of cancer risk in an appropriate manner.[18-20] In contrast, Livaudais-Toman et al found that screening patients with BreastCARE did not improve the number of women accurately identifying their cancer risk.[21] Bernat et al similarly found an educational intervention to be ineffective in improving accuracy of cancer risk perception in women.[22] However, in our study, 81 (65.3%) participants assessed their risk correctly on the initial survey, which increased to 84 (67.7%) on the post-test, an increase which was not significant. These numbers are similar to those in the study from Livaudais-Toman et al, where risk was accurately perceived at baseline by 70% of those in the control arm and 66% in the intervention arm.[21] We found a significant difference in the number of participants who rated their risk correctly on the post-test when stratified by their baseline perceived risk. Those who perceived themselves as high risk were the most likely to be correct.

Our completion rate was 16.6% among high-risk women who scheduled a genetic counseling appointment. Although this number seems low, it is similar to what other screening studies have found. Kne et al reported that only 8% of high-risk women in their research ended up completing a genetic counseling appointment upon recommendation for an appointment.[23] Other studies that similarly offered free genetic counseling and testing have reported compliance rates from 30% to 50% among high-risk women.[24-26] Rahm et al reported an uptake rate up to 44% while still billing for genetic services.[27] It is important to note that these studies may

Table 3 Pre-Test Versus B-RST™ Score (Truth) Risk Ratings

	B-RST™ Result, n (%)			
	Negative-Average	Negative-Moderate	Positive	Total
Pre-test				
Average	75 (60.5)	7 (5.6)	11 (8.9)	90 (72.6)
A little higher than average	15 (9.7)	4 (3.2)	6 (4.8)	25 (20.2)
A lot higher than average	3 (2.4)	1 (0.8)	5 (4.0)	9 (7.3)
Total	90 (72.6)	12 (9.7)	22 (17.7)	124 (100.0)

Two participants were excluded from analysis for not answering the question or adding their own response.
Fisher Exact Value = 12.662 ($P = .007$).
Abbreviation: B-RST™ = Breast Cancer Genetics Referral Screening Tool.

have had higher compliance rates than our population as they did not focus on low SES women. Regardless, these seemingly low rates of adherence demonstrate a need to look further at reasons patients do not schedule or keep an appointment.

When asked why they were being seen for a screening mammogram, the majority of our participants (73; 57.9%) answered "my doctor told me to get one." This suggests that having a physician directly recommend that patients see a genetic counselor might also improve appointment rates. Numerous studies have found that majority of patients who attend genetic counseling appointments cite having a doctor recommend that they go be a primary reason they kept the appointment.[28,29] Additionally, Kne et al showed comparable results with women expressing desire to have a doctor refer them to genetics before accepting an appointment.[23] Within our own study, one participant that initially indicated interest in an appointment was scheduled by the study coordinator, but did not attend her appointment. The participant's screening mammogram lead to a diagnosis of breast cancer, for which she ended up attending a genetic counseling appointment as part of the normal clinic held at this hospital. The appointment she attended was initiated by a referral from her oncologist.

Of the 4 participants that attended genetic counseling appointments, 3 screened at positive risk and 1 screened at negative-moderate risk. One of the patients was diagnosed with breast cancer from the screening mammogram, and 1 had a personal history. Although the number of daughters did not have any significant impact on whether or not our participants attended an appointment, prior studies found that having female offspring increased the likelihood of appointment adherence.[30] The small number of women who completed a genetic counseling appointment did not allow us to evaluate the impact of risk perception on appointment adherence. The fact that close to 70% of those at high risk expressed interest in genetic counseling, however, suggests factors other than risk perception more significantly impact whether they follow-through with genetic counseling.

We found that most women who screened either negative-moderate or positive underestimated their risk on the post-test. It is possible that this underestimation of risk lead to the lower levels of appointment adherence in our study population. Fehniger et al found that women who had higher levels of breast cancer perceived risk were more likely to utilize breast screening.[31] It would follow that those with lower levels of perceived risk, such as those underestimating their risk for breast cancer, would be less inclined to follow through with appointments addressing breast cancer risk. Correcting perceived risk among those underestimating their likelihood to develop breast cancer may improve the number of women attending genetic counseling appointments in this population.

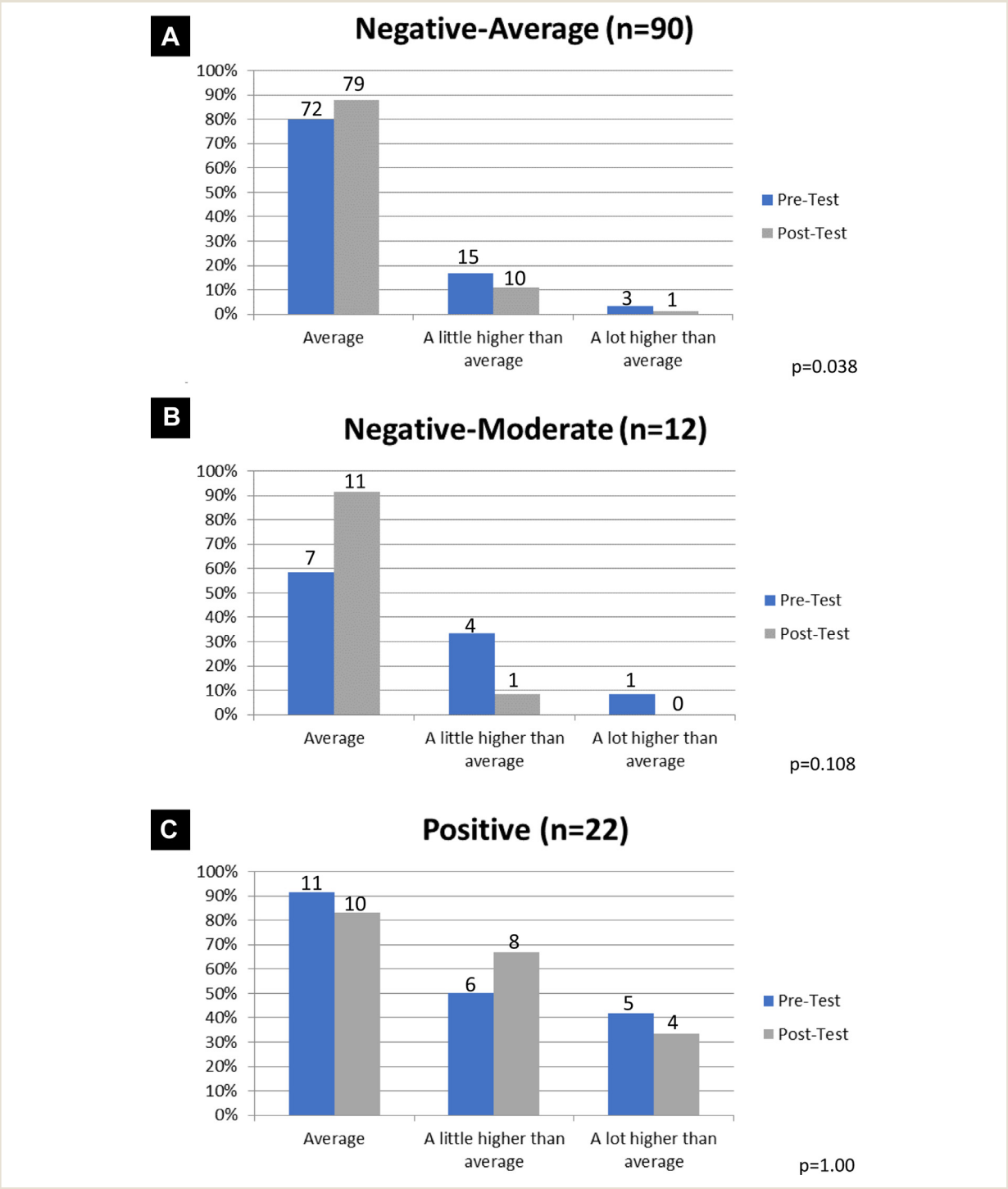
In our study, we had 17 participants answer the barrier survey. The most common barriers cited by participants included the lack of time that the participants had available to attend an extra appointment (41.2%) and participants viewing a genetic counseling appointment as unimportant (23.5%). These findings are similar to those of Geer et al, whose participants perceived no benefit from attending a genetic counseling appointment and thought the appointment would be too much of a time commitment.[32] Similarly, Kne et al found one of the top barriers to genetic counseling to be perceived lack of relevance and utility of the services.[23] The 4 participants who viewed genetic counseling as unimportant all

Table 4 Post-Test Versus B-RST™ Score (Truth) Risk Ratings

	B-RST™ Result, n (%)			
	Negative-Average	Negative-Moderate	Positive	Total
Post-test				
Average	79 (63.7)	11 (8.9)	10 (7.1)	100 (80.6)
A little higher than average	10 (8.1)	1 (0.8)	8 (6.5)	19 (15.3)
A lot higher than average	1 (0.8)	0 (0.0)	4 (3.2)	5 (4.0)
Total	90 (72.6)	12 (9.7)	22 (17.7)	124 (100.0)

Two participants were excluded from analysis for not answering the question or adding their own response.
Fisher Exact Value = 19.445 ($P < .001$).
Abbreviation: B-RST™ = Breast Cancer Genetics Referral Screening Tool.

Figure 2 Change in Risk Perception From Pre-test to Post-test in the Negative-average Screen Group (A), The Negative-moderate Screen Group (B), and The Positive Screen Group (C)



screened at negative-moderate risk, potentially playing a role in how they prioritized attending a genetic counseling appointment. Previous studies have also identified financial concerns, fear of stigmatization, fear of emotional response to results, worries about insurance coverage, and transportation as barriers that lend to lower appointment adherence rates.[23,32-34] However, in our study, all genetic services were offered at no cost to the patient. Contrary to these prior studies, one of our participants cited their lack of concern for developing breast cancer as their reason for not scheduling an appointment.[21,32-34] This low level of concern is also

observed on our surveys, where overall perceived risk to develop breast cancer was low. More women underestimating their risk on the post-test may have contributed to the lower than expected appointment attendance.

Thompson et al found that African American women with a higher risk of breast cancer, yet a lower level of knowledge about breast cancer genetics were more likely to decline genetic counseling and/or testing.[35] Similarly, Simon and Petrucelli found that lack of understanding of the risk factors for breast cancer was a significant barrier to African American women attending a genetic counseling appointment.[34] In our study population, when asked "What things do you believe impact your risk for breast cancer?" 49 (38.9%) participants either did not give an answer or wrote "I don't know." This indicates a lack of knowledge of the role of genetics and family history in the development of breast cancer and could be a reason for the low levels of appointment attendance. Prior studies demonstrate compliance with risk-reduction modalities after receiving a positive *BRCA1/2* test result. One study quantified compliance in a community setting, finding that 71% and 100% of known mutation carriers in their study population proceeded with bilateral mastectomies and bilateral salpingo-oophorectomies, respectively.[36] To our knowledge, no studies have specifically looked at compliance after genetic testing among low SES women, which may be lower. However, addressing low appointment adherence and barriers to genetic counseling can be beneficial, as women who know their cancer risk from genetic testing are more likely to remain compliant with risk-reducing guidelines.

Study Limitations

Our study has several limitations. First, we only sampled from the screening mammography clinic of one safety-net hospital. Although we recruited 126 women, which was our target sample, the results may not be generalizable to other clinic settings. Having a control group at a hospital that serves higher SES women would have been beneficial for comparison. It is a limitation that there was no documentation of how many women were informed about the study, preventing the calculation of the overall study participation rate. Our participant rate may have been impacted by limited time within the mammography setting. It is possible that non-participants would differ in key ways with respect to both risk perception and family history. Although we measured a change in risk perception, limitations of time precluded a more in-depth survey evaluation of this concept. We also were unable to evaluate whether measurements at additional time points would have led to altered risk perception. Owing to the small number of women who completed a genetic counseling appointment, we were unable to evaluate the impact on risk perception on appointment adherence.

Another limitation is that the B-RST™ is a tool designed specifically to identify women with an increased hereditary predisposition for breast cancer. It does not take into account other factors such as age at menarche, age at first live birth, age at menopause, abnormal breast biopsy, and relatives beyond second-degree relations. Using the risk assessment from B-RST™ as the "true" risk is not an entirely accurate measurement of a woman's personal risk to develop breast cancer. However, the result handout provided to each participant emphasizes the risk estimated is based on family history alone. Information on other risk factors for breast and ovarian cancer are provided, including resource links.

To address the barriers of transportation and time, future research should explore the option of tele-counseling to determine impact on adherence. Prior studies report lower appointment and genetic testing uptake when scheduled for a tele-counseling appointment, but the impact on lower SES populations should be further investigated.[37,38] Other studies might look into the best way to refer participants for genetic counseling, perhaps by having a doctor recommend it. Addressing referral methods in this setting might impact appointment adherence.

Conclusion

We showed that using B-RST™ in the screening mammography clinic of a safety net academic hospital was effective at identifying women at increased risk for HBOC. Using this tool was found to impact how women perceive their risk and, as a result, their level of interest in genetic counseling. However, although many women desired more information through a genetic counseling appointment, the low attendance rate shows a need to further assess how to increase appointment adherence. Implementing screening tools such as B-RST™ while addressing patient barriers has the potential to increase uptake of genetic counseling in high-risk women and identify women with HBOC. In turn, appropriate intervention and management can lessen the cancer incidence and mortality associated with HBOC.

Clinical Practice Points

- Lower SES is strongly associated with decreased perception of cancer risk.
- Using B-RST™ to screen family history and explaining the screen results to patients had a significant impact on cancer risk perception.
- We found improvement in risk perception accuracy from pre-test to post-test between the groups who self-rated their risk as average, a little higher than average, or a lot higher than average.

Acknowledgments

The authors would like to thank the staff at the Grady Memorial Hospital AVON Comprehensive Breast Center. They would additionally like to thank It's the Journey for providing grant funding for the program at Grady entitled 'Bridging the Gap: Genetic Access Program for Individuals at Risk for Hereditary Breast Cancer.' This work was supported by It's the Journey's, Inc. grant, 'Bridging the Gap: Genetic Access Program for Individuals at Risk for Hereditary Breast Cancer' (award number 38944); and the AVON Foundation for Women (grant number 01-2017-065).

Disclosure

The authors declare that they have no conflict of interest. The B-RST™ is the intellectual property of Emory University School of Medicine. Dr Bellcross, the developer of B-RST™, receives compensation with respect to executed licensing agreements.

References

1. Moyer VA, U.S. Preventive Services Task Force. Risk assessment, genetic counseling, and genetic testing for BRCA-related cancer in women: U.S. Preventive Services Task Force recommendation statement. *Ann Intern Med* 2014; 160:271-81.
2. Chen S, Parmigiani G. Meta-analysis of BRCA1 and BRCA2 penetrance. *J Clin Oncol* 2007; 25:1329-33.
3. Prevalence and penetrance of BRCA1 and BRCA2 mutations in a population-based series of breast cancer cases. Anglian Breast Cancer Study Group. *Br J Cancer* 2000; 83:1301-8.
4. Domchek SM, Friebel TM, Singer CF, et al. Association of risk-reducing surgery in BRCA1 or BRCA2 mutation carriers with cancer risk and mortality. *JAMA* 2010; 304:967-75.
5. Finch AP, Lubinski J, Moller P, et al. Impact of oophorectomy on cancer incidence and mortality in women with a BRCA1 or BRCA2 mutation. *J Clin Oncol* 2014; 32:1547-53.
6. Rebbeck TR, Friebel T, Lynch HT, et al. Bilateral prophylactic mastectomy reduces breast cancer risk in BRCA1 and BRCA2 mutation carriers: the PROSE Study Group. *J Clin Oncol* 2004; 22:1055-62.
7. Bellcross CA. Further development and evaluation of a breast/ovarian cancer genetics referral screening tool. *Genet Med* 2010; 12:240.
8. Bellcross CA, Lemke AA, Pape LS, Tess AL, Meisner LT. Evaluation of a breast/ovarian cancer genetics referral screening tool in a mammography population. *Genet Med* 2009; 11:783-9.
9. Bellcross C, Hermstad A, Tallo C, Stanislaw C. Validation of Version 3.0 of the Breast Cancer Genetics Referral Screening Tool (B-RST^{TM}). *Genet Med* 2019; 21:181-4.
10. U.S. Preventive Services Task Force. Genetic risk assessment and BRCA mutation testing for breast and ovarian cancer susceptibility: recommendation statement. *Ann Intern Med* 2005; 143:355-61.
11. National Comprehensive Cancer Network. Clinical practice guidlines in oncology. Genetic/familial high-risk assessment: breast and ovarian. Version.I.2018. 2017. Available at: https://www.nccn.org/professionals/physician_gls/default.aspx#detection. Accessed: December 13, 2017.
12. Sabik LM, Tarazi WW, Bradley CJ. State Medicaid expansion decisions and disparities in women's cancer screening. *Am J Prev Med* 2015; 48:98-103.
13. Akinyemiju T, Ogunsina K, Sakhuja S, Ogbhodo V, Braithwaite D. Life-course socioeconomic status and breast and cervical cancer screening: analysis of the WHO's Study on Global Ageing and Adult Health (SAGE). *BMJ Open* 2016; 6:e012753.
14. Ku L, Bysshe T, Steinmetz E, Bruen BK. Health reform, medicaid expansions, and women's cancer screening. *Womens Health Issues* 2016; 26:256-61.
15. Pagan JA, Brown CJ, Asch DA, Armstrong K, Bastida E, Guerra C. Health literacy and breast cancer screening among Mexican American women in South Texas. *J Cancer Educ* 2012; 27:132-7.
16. National Cancer Institute. Psychosocial issues in inherited breast and ovarian cancer syndromes. 2017. Available at: https://www.cancer.gov/types/breast/hp/breast-ovarian-genetics-pdq#section/_271. Accessed: November 30, 2017.
17. Grady Community Health needs assessment. 2016. Available at: https://www.gradyhealth.org/resources/pdfs/GHS%20Community%20Health%20Needs%20Assessment%202016.pdf. Accessed: November 30, 2017.
18. Keohane D, Lehane E, Rutherford E, et al. Can an educational application increase risk perception accuracy amongst patients attending a high-risk breast cancer clinic? *Breast* 2017; 32:192-8.
19. Lerman C, Lustbader E, Rimer B, et al. Effects of individualized breast cancer risk counseling: a randomized trial. *J Natl Cancer Inst* 1995; 87:286-92.
20. Matloff ET, Moyer A, Shannon KM, Niendorf KB, Col NF. Healthy women with a family history of breast cancer: impact of a tailored genetic counseling intervention on risk perception, knowledge, and menopausal therapy decision making. *J Womens Health (Larchmt)* 2006; 15:843-56.
21. Livaudais-Toman J, Karliner LS, Tice JA, et al. Impact of a primary care based intervention on breast cancer knowledge, risk perception and concern: a randomized, controlled trial. *Breast* 2015; 24:758-66.
22. Bernat JK, Hullmann SE, Sparks GG. Communicating breast cancer risk information to young adult women: a pilot study. *J Psychosoc Oncol* 2017; 35:249-59.
23. Kne A, Zierhut H, Baldinger S, et al. Why is cancer genetic counseling underutilized by women identified as at risk for hereditary breast cancer? Patient perceptions of barriers following a referral letter. *J Genet Couns* 2017; 26:697-715.
24. Culver JBW, Yasui Y, Durfy S, Press N. Participation in breast cancer genetic counseling: the influence of educational level, ethnic background, and risk perception. *J Genet Couns* 2001; 10:215-31.
25. Geller G, Doksum T, Bernhardt BA, Metz SA. Participation in breast cancer susceptibility testing protocols: influence of recruitment source, altruism, and family involvement on women's decisions. *Cancer Epidemiol Biomarkers Prev* 1999; 8:377-83.
26. O'Neill SM, Peters JA, Vogel VG, Feingold E, Rubinstein WS. Referral to cancer genetic counseling: are there stages of readiness? *Am J Med Genet C Semin Med Genet* 2006; 142C:221-31.
27. Rahm AK, Sukhanova A, Ellis J, Mouchawar J. Increasing utilization of cancer genetic counseling services using a patient navigator model. *J Genet Couns* 2007; 16:171-7.
28. Anderson B, McLosky J, Wasilevich E, Lyon-Callo S, Duquette D, Copeland G. Barriers and facilitators for utilization of genetic counseling and risk assessment services in young female breast cancer survivors. *J Cancer Epidemiol* 2012; 2012:298745.
29. Chin TM, Tan SH, Lim SE, et al. Acceptance, motivators, and barriers in attending breast cancer genetic counseling in Asians. *Cancer Detect Prev* 2005; 29:412-8.
30. Ayme A, Viassolo V, Rapiti E, et al. Determinants of genetic counseling uptake and its impact on breast cancer outcome: a population-based study. *Breast Cancer Res Treat* 2014; 144:379-89.
31. Fehniger J, Livaudais-Toman J, Karliner L, et al. Perceived versus objective breast cancer risk in diverse women. *J Womens Health (Larchmt)* 2014; 23:420-7.
32. Geer KP, Ropka ME, Cohn WF, Jones SM, Miesfeldt S. Factors influencing patients' decisions to decline cancer genetic counseling services. *J Genet Couns* 2001; 10:25-40.
33. Adams I, Christopher J, Williams KP, Sheppard VB. What black women know and want to know about counseling and testing for BRCA1/2. *J Cancer Educ* 2015; 30:344-52.
34. Simon MS, Petrucelli N. Hereditary breast and ovarian cancer syndrome: the impact of race on uptake of genetic counseling and testing. *Methods Mol Biol* 2009; 471:487-500.
35. Thompson HS, Valdimarsdottir HB, Duteau-Buck C, et al. Psychosocial predictors of BRCA counseling and testing decisions among urban African-American women. *Cancer Epidemiol Biomarkers Prev* 2002; 11:1579-85.
36. Morgan D, Sylvester H, Lucas FL, Miesfeldt S. Cancer prevention and screening practices among women at risk for hereditary breast and ovarian cancer after genetic counseling in the community setting. *Fam Cancer* 2009; 8:277-87.
37. Buchanan AH, Datta SK, Skinner CS, et al. Randomized trial of telegenetics vs. in-person cancer genetic counseling: cost, patient satisfaction and attendance. *J Genet Couns* 2015; 24:961-70.
38. Fournier DM, Bazzell AF, Dains JE. Comparing outcomes of genetic counseling options in breast and ovarian cancer: an integrative review. *Oncol Nurs Forum* 2018; 45:96-105.