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Awareness and acceptability of population-based screening for pathogenic *BRCA* variants: Do race and ethnicity matter?

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HIGHLIGHTS

- Interest in population-based *BRCA* screening was high among a diverse, unselected population.
- Willingness to pay out of pocket was associated with interest in testing.
- Awareness of *BRCA* testing is poor among Black and Hispanic women when compared to White and non-Hispanic women.

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ABSTRACT

Objective. To evaluate awareness and acceptability of population-based *BRCA* testing among an unselected population of women presenting for annual gynecologic health assessment, with secondary objective to determine if a racial disparity exists in acceptability and awareness of this screening strategy.

Methods. Women presenting for routine gynecologic care in an outpatient setting of a single academic institution were anonymously surveyed. Survey collected age, self-identified race and ethnicity, education level, personal and family history of breast and/or ovarian cancer (BOC), awareness and interest, and willingness to pay out of pocket for testing. Responses were compared with bivariate and multivariate analysis.

Results. Interest in testing was expressed in 150 of 301 (45.1%) of participants. Women with a family history of BOC were more likely to be interested in testing than those without (OR = 1.9 (1.0–3.6)). Interest in testing was associated willingness to pay (OR = 3.3 (1.7–6.4)). Higher education level was associated with awareness of testing (OR = 9.9 (2.0–49.7)). Interest in testing was similar between racial groups, but awareness and willingness to pay for testing were higher among White women. Multivariate analysis with adjustment for education level confirmed that Black and Hispanic women were less likely to have awareness of genetic testing compared to White women and non-Hispanic Women, respectively (OR = 0.11 (0.05–0.3); OR = 0.10 (0.01–0.8)).

Conclusions. Interest in genetic testing among women in the general population is high. Despite interest, awareness of *BRCA* is poor among Black and Hispanic women even when adjusting for education level.

1. Introduction

Ovarian cancer remains the most lethal gynecologic malignancy largely because a majority of patients present with advanced stage disease at initial diagnosis [1]. Multiple prospective population based trials have failed to demonstrate a benefit of screening programs for early detection of this disease [2–5], further highlighting the importance of prevention strategies to improve disease outcomes. With advances in understanding of pathogenic genetic variants in genes such as *BRCA1/2*, women at high risk of developing ovarian cancer when identified can utilize risk reducing strategies to lower ovarian cancer incidence and mortality [6–8].

Current recommendations to identify patients at genetic risk for ovarian cancer include referral for genetic cancer risk assessment (GCRA) based on family history and personal cancer diagnosis. Once a

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specific pathogenic genetic variant is identified "cascade testing" or testing of blood relatives of the affected individual can be performed [9,10]. Several barriers exist with current screening strategy: it relies on patients to know and report significant family history, practitioners to accurately assess and interpret complex referral criteria, and it excludes those with pathogenic *BRCA1/2* variants with no known family history.

In 2007, National Comprehensive Cancer Network (NCCN) recommended genetic testing for all women diagnosed with epithelial ovarian, fallopian tube, and primary peritoneal cancers, regardless of their age at diagnosis or family history of cancer. Despite this recommendation, implementation of genetic testing in the United States remains poor with only 12–31% of ovarian cancer patients undergoing testing [11,12]. Additionally, disparities in utilization of genetic counseling services have been demonstrated with Black women significantly underutilizing GCRA compared to White women [13]. Various reasons have been suggested for this trend including poor access, limited knowledge regarding how to pursue services, lower referral rates and mistrust of medical institutions [14,15].

A population-based screening strategy, where all women, regardless of personal or family history, undergo genetic testing after age 30, is an alternative strategy that could address the challenges of cascade testing and potentially abrogate racial disparity by improving access [16]. Expansion of screening to an unselected population has not been extensively studied, and assessment of patient awareness and acceptability of this screening approach is warranted. The overall goal of this study is to address the acceptability of a population-based screening strategy for pathogenic *BRCA* variants and to elucidate racial disparity in patient awareness and interest in genetic screening.

2. Methods

2.1. Survey participants

Following approval from the Virginia Commonwealth Institutional Review Board, a cross-sectional survey of unselected women presenting for routine annual gynecologic health assessment was performed between April to May 2018. The anonymous written survey was provided to a convenience sample of women who could read and write English in an outpatient setting of a single academic institution. Potential participants were identified by front desk office staff based on appointment type recorded in outpatient electronic scheduling system and were provided a survey at the time of registration for annual gynecologic exam appointment. Completed surveys were then returned by patients to a secure drop-box and collected by study staff.

2.2. Survey instrument

The self-administered written survey included a patient education page that outlined explanation of *BRCA*1/2 genes and current recommendations regarding testing based on NCCN guidelines. Because among the known genetic variants, *BRCA1/2* confer the highest risk of hereditary breast and ovarian cancer, we chose to focus our questions on these genes. Participants were asked to identify their age, race, ethnicity, education level, and personal and family history of breast and/or ovarian cancer (BOC). Survey questions were modeled after a study conducted by Adams et al. [17] with additional input from our interdisciplinary research team. The survey included closed-ended questions regarding awareness of genetic testing (e.g. Have you heard of genetic testing for breast and ovarian cancer risk?), acceptability of genetic testing (e.g. If you had the opportunity, would you be interested in genetic testing for breast and ovarian cancer risk?), and willingness to pay for testing (e.g. Would you be willing to pay out of pocket for genetic testing for breast and ovarian cancer risk?). Two open ended questions were included to assess motivators and barriers to pursue testing (e.g. What would motivate/discourage you from participating in genetics testing?). Complete survey is available in Supplementary materials.

2.3. Data analysis

For close ended questions, descriptive data was summarized with mean and standard deviation for age and proportions and percentages for all other categorical variables. Those who identified as races other than White and Black were categorized as Other. Survey responses were compared between races using chi square test. Multivariate analysis was performed using logistic regression model to evaluate covariates associated with knowledge and acceptability of *BRCA* testing. Open ended responses were reviewed by research team to identify consistent themes for descriptive reporting. Data were analyzed using JMP statistical software, version 14, SAS Institute Inc., Cary, NC, 1989–2019.

3. Results

Of the 323 participants included in the study, 36.5% (n = 118/323) self-identified as White, 50.5% (n = 163/323) as Black, 12.1% (n = 39/323) identified as Other, and 1% (n = 3/323) did not disclose race. 18 of 276 (6.5%) participants identified their ethnicity as Hispanic. Majority of participants (225/317, 71%) had above a high school education level. Only 7 of 319 (2.2%) participants identified a personal history of breast and/or ovarian cancer, while 128 of 310 (41.3%) participants reported a family history of breast and/or ovarian cancer (Table 1).

Interest in *BRCA* testing was expressed in nearly half of the participants (150/301, 45.1%). On multivariate analysis, women with a family history of BOC were more likely to be interested in *BRCA* testing than those without (OR = 1.9 (1.0–3.6), p = 0.04). Interest in *BRCA* testing was associated with willingness to pay out of pocket (OR = 3.26 (1.7–6.4), p < 0.01). Responses regarding specific amount of money participants were willing to pay is illustrated in Table 2. When surveyed regarding *BRCA* awareness, 68.9% of participants had no previous knowledge of *BRCA* testing. On multivariate analysis, higher education level was associated with awareness of *BRCA* testing (OR = 9.9 (1.9–49.7), p < 0.01). Results of multivariate analysis are summarized in Table 3.

Significant differences were identified between races in both education level and awareness of *BRCA* testing. Over 90% of White participants (n = 110) had more than a high school education compared to 50% (n = 82) of Black women and 86.8% (n = 33) of Other women (p < 0.01). Over half of White women (57.6% n = 68) reported awareness of *BRCA* testing compared to 11.4% (n = 18) of Black women and 30.8% (n = 12) of Other women (p < 0.01). There were no significant differences found in interest in *BRCA* testing and personal or family history of BOC between groups on bivariate analysis (Table 4). Multivariate analysis with adjustment for education level confirmed that Black and Hispanic women were less likely to have awareness of *BRCA* testing compared to White women (OR = 0.11 (0.05–0.28), p < 0.01; OR = 0.10 (0.01–0.83), p = 0.03).

In review of motivations and deterrents to pursue *BRCA* testing, several themes were identified from open ended survey questions. Among those interested in *BRCA* testing, common motivators to proceed with

Table 1
Demographic characteristics.

Age, mean ± SD	37.7 ± 12.6
Race, n (%)	
White	118 (36.5%)
Black	163 (50.5%)
Other	39 (12.1%)
Ethnicity, n (%)	
Hispanic	18 (6.5%)
Non-Hispanic	258 (93.5%)
Education level, n (%)	
High school or less	92 (29%)
Some college or more	225 (71%)
Personal history of breast and/or ovarian cancer, n (%)	7 (2.2%)
Family history of breast and/or ovarian cancer, n (%)	128 (41.3%)

Table 2
Willingness to pay for BRCA testing.

	Total n (%)	White n (%)	Black n (%)	Other n (%)
None	155 (58.5%)	42 (42.9%)	96 (71.1%)	17 (53.1%)
Up to $50	59 (22.3%)	22 (22.5%)	28 (20.7%)	9 (28.1%)
Up to $100	27 (10.2%)	18 (18.4%)	7 (5.2%)	2 (6.3%)
Up to $500	20 (7.6%)	12 (12.2%)	4 (3%)	4 (12.5%)
More than $500	4 (1.5%)	4 (4.1%)	0 (0%)	0 (0%)

testing were desire for knowledge of personal health risks, a family history of cancer, potential impact on other family members including children, and impact on future preventative measures or risk reducing treatment. For those not interested in testing, deterrents included lack of family history, potential costs, anxiety regarding positive results, and lack of information regarding testing.

4. Discussion

This study found that acceptability of population-based *BRCA* screening within an unselected population of patients is high, with nearly half of participants attending routine annual gynecologic health assessment indicating an interest in *BRCA* testing. Population-based *BRCA* testing has been proposed as a screening strategy to overcome limitations of the current personal/family history based criteria [16,18]. Our current screening strategy relies on a complex referral pathway where both patients and health care professionals have to identify family history and recognize its importance to initiate referral. This current system of referrals to genetic testing has led to an underutilization of services.

Reliance on family history to identify women at high risk is also problematic as up to half of women with ovarian cancer who test positive for a pathogenic *BRCA* variant will have no family history of breast or ovarian malignancy [19]. Implementation of risk based genetic testing strategies to date have been disappointing. Despite recommendations that all women with a personal history of ovarian cancer receive genetic testing, nearly 90%, an estimated 1.2 million individuals, did not receive recommended testing in the United States in 2015 [11]. A recent assessment of women with breast and ovarian cancer from SEER sites with linkage to germline cancer genetic testing revealed that only 24% of eligible breast cancer patients and 31% of ovarian cancer patients underwent testing in 2013 and 2014 [12].

Evidence suggests implementation of unselected *BRCA* testing in high prevalence populations, such as women of Ashkenazi Jewish descent is a cost effective and acceptable screening strategy [20–23]. Little is known regarding acceptability of population-based *BRCA* screening in a larger, average-risk population. A survey study of women with no personal history of ovarian cancer in the United Kingdom found that 74% of participants expressed a willingness to participate in genetic testing to determine ovarian cancer risk [24]. The majority of participants in this study were White and educated to college degree level. Our data adds to this research by showing that within a diverse, general population unselected for race or ethnicity, education or personal or family history there is high interest in *BRCA* screening.

Potential negative impacts of population-based genetic screening have been suggested including misinterpretation of results like variants of unknown significance [25] and discrimination in health coverage and/or employment based on genetics testing results [26]. In a study of barriers and facilitators of genetics testing among breast cancer survivors, fear of genetic discrimination was cited as a barrier in <10% of Non-Hispanic white participants and only one Hispanic participant [27]. Similarly, in our study, privacy issues were not identified by patients as a main deterrent to genetic testing.

In this study, over 40% of our survey respondents were willing to pay up to $50 for testing. Following the Supreme Court's 2013 ruling on *BRCA* patenting, the cost of testing has declined significantly but typically remains over this threshold. Those women interested in screening were more likely to express willingness to pay out of pocket for testing, suggesting that cost does play a role in interest. Although most insurance companies cover the cost of *BRCA* testing for populations indicated by the NCCN guidelines, many patients may still incur out of pocket costs associated not just with genetic testing itself, but also with the downstream costs of additional screening and surgery incurred should a pathogenic germline variant be identified. Previous research has demonstrated that women without cost barriers to testing are more likely to complete genetic testing [28].

Our data has also echoed previous studies indicating high interest for *BRCA* testing, but poor awareness among non-White women. We found a significant difference in awareness of *BRCA* testing between White and Black women that persisted even after adjusting for education level. This knowledge gap has been described as a leading reason why Black and Hispanic women are reluctant to undergo testing compared to White women even following referrals [29]. Educational programs to increase awareness of *BRCA* testing are needed in order to address this disparity.

Table 3
Multivariate analysis of survey responses.

Survey response	Have you heard of BRCA testing? Adjusted odds ratio for positive response (95% CI)	p value	Would you be interested in BRCA testing? Adjusted odds ratio for positive response (95% CI)	p value
Age	1.03 (0.99–1.06)	0.15	0.97 (0.95–1.0)	0.06
Race				
White	Ref		Ref	
Black	0.11 (0.05–0.28)	<**0.01**	1.38 (0.60–3.15)	0.45
Other	0.48 (0.17–1.32)	0.16	1.13 (0.41–3.11)	0.81
Ethnicity				
Non-Hispanic	Ref		Ref	
Hispanic	0.10 (0.01–0.83)	**0.03**	1.99 (0.47–8.50)	0.35
Education level				
High school or less	Ref		Ref	
Some college or more	9.93 (1.98–49.7)	<**0.01**	1.46 (0.60–3.55)	0.40
Family history of breast and/or ovarian cancer				
No	Ref		Ref	
Yes	0.90 (0.42–1.91)	0.78	1.91 (1.00–3.63)	**0.04**
Willing to pay out of pocket				
No	Ref		Ref	
Yes	0.78 (0.35–1.73)	0.53	3.26 (1.67–6.35)	<**0.01**

p value < 0.05 illustrated in bold.

Table 4
Comparison of survey responses by race.

	White n = 118 (36.9%)	Black n = 163 (50.9%)	Other n = 39 (12.2%)	p value
Age, mean ± SD	37.4 ± 12.4	38.9 ± 13.3	33.3 ± 9.9	0.05
Ethnicity, n (%)				
Hispanic	8 (7.1%)	2 (1.5%)	8 (23.5%)	<**0.01**
Non-Hispanic	104 (92.9%)	128 (98.5%)	26 (76.5%)	
Education Level, n (%)				
High school or less	7 (6.0%)	80 (49.4%)	5 (13.2%)	<**0.01**
Some college or more	110 (94.0%)	82 (50.6%)	33 (86.8%)	
Personal history of breast and/or ovarian cancer, n (%)				
Yes	3 (2.5%)	4 (2.5%)	0 (0%)	0.62
No	115 (97.5%)	159 (97.6%)	38 (100%)	
Family history of breast and/or ovarian cancer, n (%)				
Yes	49 (42.6%)	68 (42.8%)	11 (30.6%)	0.38
No	66 (57.4%)	91 (57.2%)	25 (69.4%)	
Awareness of BRCA testing, n (%)				
Yes	68 (57.6%)	18 (11.4%)	12 (30.8%)	<**0.01**
No	50 (42.4%)	140 (88.6%)	27 (69.2%)	
Interest in BRCA testing, n (%)				
Yes	51 (48.1%)	57 (60.1%)	22 (56.4%)	0.14
No	55 (51.9%)	86 (39.9%)	17 (43.6%)	
Willing to pay out of pocket, n (%)				
Yes	56 (57.1%)	39 (28.9%)	15 (46.9%)	<**0.01**
No	42 (42.9%)	96 (71.1%)	17 (53.1%)	

Racial disparities in utilization of GCRA are another limitation of our current screening strategy and have been previously described [30]. While interest in GCRA is high, knowledge and actual utilization of genetic testing services is low among Black women [31–33]. A study of 92 mostly Black Medicare beneficiaries from the Southern Community Cohort Study, found that only 8.7% of breast and ovarian cancer patients meeting Medicare criteria for genetic testing underwent genetic testing with a median follow-up time of 5 years post diagnosis [34]. There is evidence of bias among health care providers, with studies showing lower referral rates for GCRA among Black and Hispanic patients [35,36]. Further complicating our understanding of disparities in genetic testing, non-White women may be less likely to disclose results to family members to initiate cascade testing [37]. Population-based testing without selection for personal or family history of cancer could reduce these barriers to testing in non-White populations, thereby decreasing racial disparities.

Limitations of this study include possible selection bias given the voluntary nature of the survey. The survey was provided in English only, thus excluding those who are unable to read/write in English. With predominately close-ended questions, we were unable to fully explore patients' attitudes towards testing. Previous genetic testing was not assessed in this survey, but would be anticipated to be low. However, this survey is one of the few studies that investigates awareness and acceptability of *BRCA* testing among an unselected diverse patient population.

Population-based *BRCA* testing has the potential to address many of the limitations of our current screening strategy and could decrease racial disparities in genetic testing by expanding access. In conclusion, our study demonstrates that a general population of patients are interested in *BRCA* testing. However, focus is needed on increasing knowledge of *BRCA* testing among non-White women.

Author contribution

Study concept/design: LR, JQ, ST.
IRB application and approval: LR, JQ, ST.
Data collection: LR, AK.
Data analysis and review: LR, AK, JQ, SG, SS, AS, VS, ST.
Manuscript writing and editing: LR, AK, JQ, SG, SS, AS, VS, ST.

Declaration of Competing Interest

The authors whose names are listed immediately below certify that they have NO affiliations with or involvement in any organization or entity with any financial interest (such as honoraria; educational grants; participation in speakers' bureaus; membership, employment, consultancies, stock ownership, or other equity interest; and expert testimony or patent-licensing arrangements), or non-financial interest (such as personal or professional relationships, affiliations, knowledge or beliefs) in the subject matter or materials discussed in this manuscript.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.ygyno.2019.06.009.

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