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Racial disparities in *BRCA* testing and cancer risk management across a population-based sample of young breast cancer survivors

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Abstract

Background—Breast cancer (BC) disparities may widen with genomic advances. We compared non-Hispanic white (NHW), Black, and Hispanic BC survivors for: 1) cancer risk management practices (CRM) among *BRCA* carriers; and 2) provider discussion and receipt of genetic testing.

Methods—A population-based sample of NHW, Black, and Hispanic women diagnosed with invasive BC ≤ age 50 in 2009–2012 were recruited through the state cancer registry. Using multiple logistic regression we compared CRM in *BRCA* carriers and association of demographic and clinical variables with provider discussion and receipt of testing.

Results—Of the 1622 participants, 36.1% (159/440) Blacks, 64.5% (579/897) NHW, 49.6% (58/117) Spanish-speaking Hispanics, and 69.0% (116/168) English-speaking Hispanics had *BRCA* testing, of whom 90 had a pathogenic *BRCA* mutation. Among *BRCA* carriers, RRM and RRSO rates were significantly lower among Blacks compared to Hispanics and NHW after controlling clinical and demographic variables (p=0.025 and 0.008, respectively). Compared to NHW, discussion of genetic testing with a provider was 16 times less likely among Blacks (p<0.0001) and nearly two times less likely among Spanish-speaking Hispanics (p=0.04) after controlling clinical and sociodemographic factors.

Conclusions—Our results suggest lower rates of RRSO among Black compared to Hispanic and NHW *BRCA* carriers, which is concerning as benefits from genetic testing arise from CRM options. Furthermore, lower *BRCA* testing rates among Blacks may partially be due to lower

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likelihood of provider discussion. Future studies are needed to improve cancer risk identification and management practices across all populations to prevent the widening of disparities.

Introduction

Breast cancer (BC) is the most common cancer among women in the United States, with 5–10% due to inherited gene mutations most commonly in the *BRCA1* and *BRCA2* (*BRCA*) genes.[1, 2] *BRCA* mutation carriers have a 60–70% lifetime risk of BC and up to a 44% risk of ovarian cancer,[3–6] compared to 12% and <2% for women in the general population. Furthermore, the risk of a second primary BC among *BRCA* mutation carriers may be over 50%, particularly among those who develop their first BC at an early age.[7, 8] These risks may be reduced by 90% or more (i.e., to below that of the general population) through preventive options such as risk-reducing mastectomy (RRM) and risk-reducing salpingo-oophorectomy (RRSO).[9, 10] Once an individual is tested for and identified to have inherited cancer predisposition, they will only reap health benefits from acting on this information. Consequently, clinical practice guidelines in the United States (US) for *BRCA* carriers have been developed through the National Comprehensive Cancer Network (NCCN) including: 1) annual BC surveillance (through mammogram and breast MRI) or RRM for BC risk management; and 2) RRSO for ovarian cancer risk management.[11]

Prior efforts to explore cancer risk management practices among *BRCA* carriers have primarily been based on non-Hispanic White (NHW) populations at academic institutions[12–15] or integrated health systems.[16] Studies among US-based women consistently suggest higher rates of RRSO (~70%) than RRM (~40%).[12–16] Yet no prior efforts have compared cancer risk management across ethnically and racially diverse populations with *BRCA* mutations, treated across varied settings.

Identification of a *BRCA* mutation has potential to empower women with options to detect cancers early or prevent them altogether.[17–19] Yet only ~10% of those with *BRCA* mutations in the US are aware they carry a mutation.[20] Furthermore, there are substantial disparities across populations in awareness and utilization of genetic testing for inherited BC, with considerably lower rates reported among Blacks and Hispanics compared to NHW.[21–24] Per NCCN guidelines, all women diagnosed with BC ≤50 should be offered cancer genetic risk assessment (which includes genetic counseling and consideration for testing),[11] yet few discuss testing with their healthcare provider.[25–28]

Through a population-based sample of young Black, Hispanic, and NHW women with BC, we sought to compare: 1) cancer risk management practices among *BRCA* carriers; and 2) provider discussion and receipt of genetic testing.

Methods

Participants

Eligible participants were women diagnosed with invasive BC ≤50 between the years 2009–2012 living in Florida at the time of diagnosis, and alive at the time of recruitment. Through protocols approved through the Institutional Review Boards at the University of South

Florida and the Florida Department of Health, recruitment of Black women was initiated in 2012 as previously described, [29, 30] and that of White and Hispanic women was initiated in 2014. Using information on all eligible participants released by the Florida State Cancer Registry, contact was attempted among all Black and Hispanic women in the sampling frame and in a random sample of White women (Figure 1).

Participants were recruited using previously described state-mandated recruitment methods,[29, 30] which consisted of 2 mailings, 3 weeks apart, including a 'telephone response card' to give potential participants the option to either decline (i.e., indicating they did not wish to be contacted by phone) or express interest in participation with follow-up by a study team member. If no response was received within 3 weeks of the second mailing, a member of the study team attempted to contact the potential participant by telephone to explain the study and determine interest in participation. For those willing to participate, written informed consent was obtained and a baseline study questionnaire was completed.

Measures

Clinical (i.e., age at diagnosis, stage of diagnosis, histologic subtype, tumor receptor status) and demographic (i.e., primary payer at diagnosis, race/ethnicity) data were obtained from the cancer registry for all potential participants meeting inclusion criteria. Tumor receptor status was coded as triple negative (TN) if registry data indicated the tumor was negative for all three receptors (ER, PR, and HER2) and non-triple negative (non-TN) if at least one of these receptors was present. Tumors that were missing data for one or more receptors, but were negative for the other receptors were categorized as undetermined. For all participants in the undetermined group, clarification was attempted through medical record verification and patient self-report. Data obtained through the baseline questionnaire included healthcare provider discussion of genetic testing for inherited cancer risk, and receipt of *BRCA* testing. Medical record verification was attempted in all participants who indicated receipt of *BRCA* testing in whom a signed a medical release was available. Participants were categorized through self-reported race/ethnicity into NHW, Black, and Hispanic groups. Hispanics were further categorized as Spanish-speaking (if they spoke Spanish at home) or English-speaking (all others). Additional information obtained through the baseline questionnaire included: partner status, biological children, income, family cancer history, education, insurance status and cancer risk management (including receipt of an RRSO, RRM; and high-risk BC screening (mammograms and breast MRIs).

Data Analysis

Demographic and clinical characteristics available through the cancer registry for all eligible participants were summarized for each racial/ethnic strata using descriptive statistics. Consented participants in each racial/ethnic strata were compared to all other presumed eligible women from the cancer registry using Pearson's chi-square tests. For participants in each of the four racial/ethnic groups, demographic and clinical characteristics were summarized and compared using Pearson's chi-square tests for categorical variables and Mann-Whitney test for continuous variables.

Among those with a known *BRCA* mutation at the time of the baseline questionnaire, proportions with RRSO, RRM and breast surveillance were calculated based on self-report. Comparisons between Blacks, Hispanics and NHW were made using multiple logistic regression to control for age at enrollment, time since diagnosis, income, family history of breast and ovarian cancer, and private insurance at diagnosis. Analyses were conducted using SAS version 9.4. The goodness-of-fit for all regression models was evaluated by the Hosmer-Lemeshow statistic. For all analyses, a two-sided p-value of <0.05 was considered statistically significant.

Proportion who discussed genetic testing with a healthcare provider and proportion who underwent genetic testing were calculated for each racial/ethnic strata. Two multiple logistic regression models were then conducted using the 1,325 cases for whom all data were available. The first regression model evaluated racial/ethnic differences in genetic testing discussion and the second model evaluated receipt of genetic testing. To simultaneously control for key variables and evaluate the relative strength of relationship between the two outcomes (i.e., discussed testing and receipt of testing), a path model was conducted using Mplus version 6.12. Variables with a p-value <0.15 from the two logistic regression models were included in the model as follows. Race/ethnicity, having children, diagnosed at or below age 45, annual income over $25,000, college educated, family history of breast cancer, and having private insurance were included as predictors of having testing. Simultaneously, race/ethnicity, having children, triple negative tumor, diagnosed at or below age 45, annual income over $25,000, college educated, family history of breast cancer, family history of ovarian cancer, having private insurance, and years from diagnosis to survey were included as predictors for receipt of testing. A direct path was included to evaluate the strength of relationship between discussed testing and receipt of testing while controlling for all other variables specified in the path model.

Results

Participants included a total of 1622 BC survivors, consisting of 440 Blacks, 168 English-speaking Hispanics, 117 Spanish-speaking Hispanics, and 897 NHW (Figure 1). Comparisons between participants and all others within each respective racial/ethnic strata revealed no statistically significant differences with regard to median age, stage, histologic subtype, marital status, or employment at diagnosis (results not shown). Among those reporting genetic testing, medical record verification was obtained in 72% overall, and 78% of *BRCA* carriers. Participants differed across racial/ethnic strata on several clinical and demographic variables (Table 1).

Among NHW, Black and Hispanic *BRCA* carriers, uptake of: 1) RRSO was 76.6%, 28.1%, and 90.9%, respectively; 2) RRM was 95.7%, 68.8%, and 81.8%, respectively; and 3) guideline-based BC screening or RRM was 100%, 85.7%, and 100%, respectively (Figure 2). Among *BRCA* carriers with remaining breast tissue who reported no breast screening, 2 had not yet completed their BC treatment, both of whom were Black. With Blacks as the referent group, even after controlling for possible confounders, Hispanics and NHW remained significantly more likely to have RRSO (p=0.025) and RRM (p=0.008). Hosmer-

Lemeshow tests provided evidence of adequate model fit for all logistic regression models (all p>0.05).

All participants met national guidelines for genetic risk assessment and counseling;[31] however, among Blacks, Spanish-speaking Hispanics, English-speaking Hispanics and NHW, the proportion who reported: 1) having discussed genetic testing with a provider was 37.3%, 70.1%, 85.7% and 85.7%, respectively; and 2) receipt of genetic testing was 36.1%, 49.6%, 69.05%, and 64.55%, respectively. Compared to NHW, Blacks were 16.6 times less likely to have discussed genetic testing with a healthcare provider (p<0.0001) and Spanish-speaking Hispanics were nearly two times less likely to have discussed testing (p=0.04) after controlling for other variables (Table 2). Rates of genetic testing discussion were similar among NHW and primarily English-speaking Hispanics.

Blacks were 5.6 times less likely to have had genetic testing than NHW when controlling for other variables (Table 2), but differences between NHW and Spanish-speaking Hispanics were no longer significant (p=0.82) after controlling for clinical and socioeconomic differences. The path model reveals the strongest association with receipt of testing is having a healthcare provider discuss testing (Figure 3).

Discussion

To our knowledge, this is the first study to compare differences in cancer risk management practices across an ethnically and racially diverse sample of *BRCA* mutation carriers tested and treated across multiple settings. Our findings suggest lower rates of RRSO and RRM among Blacks. Furthermore, our results demonstrate lower genetic testing rates among Blacks compared to NHW, most strongly associated with lower genetic testing discussions by healthcare providers.

When considering *BRCA* testing, it is important to recognize that benefits do not arise from *BRCA* testing itself, but rather acting on test results to detect cancers early or prevent them altogether. A number of studies have evaluated cancer risk management practices among *BRCA* carriers; however, these primarily encompass NHW populations mainly based at academic institutions[12–15] or integrated health systems.[16] A recent retrospective cohort study of primarily NHW *BRCA* carriers from a community healthcare system in Northern California reported uptake of RRSO and RRM among *BRCA* carriers of 74% and 44%, respectively,[16] which is slightly higher than that recently reported from US-based academic centers.[12, 15] Similarly, uptake of preventive options reported through an international study of *BRCA* carriers reported RRSO and RRM rates of 71.1% and 36.3%, respectively, among US-based women.[13] Taken together, these RRSO rates are similar to those found in our study among NHW and Hispanics, yet substantially higher than the RRSO rate of 28% observed among Blacks in our study. Consistent with the low RRSO rates we observed among Blacks are results from African American *BRCA* carriers in which breast and ovarian cancer surveillance was preferred over risk-reducing surgery, however this earlier study was based on a single African American kindred.[32] Consequently, our study represents the first to evaluate and compare follow-up care among unselected *BRCA* carriers across

minority populations, with results suggesting substantial racial differences in cancer risk management practices.

Although RRSO remains the only reliable option for ovarian cancer risk management among *BRCA* carriers, RRM or heightened screening through annual MRI and mammograms are both considered appropriate options for BC risk management.[11] However, adherence to screening over time among unaffected *BRCA* carriers in an integrated healthcare system identified low compliance with annual MRI (35%) and mammograms (43%) at baseline among those without RRM with compliance at 5 years dropping to only 3% and 7%, respectively.[16] More recently, a follow-up study of primarily NHW *BRCA* carriers who received genetic counseling and *BRCA* testing through an academic center indicated 51% had RRM and 72% had RRSO.[33] Interestingly, despite the limited number of minorities in this study (~11%; n=11), study authors reported both white race and higher BC genetics knowledge to be significantly associated with adherence to recommended management, highlighting the potential for genomic testing to widen existing disparities among minority populations. Ultimately, our study is the sole population-based effort to compare differences in cancer risk management practices across minority *BRCA* carriers treated across diverse settings, underscoring the need for further studies to confirm and address observed disparities in follow-up care.

The majority of *BRCA* testing has occurred in Caucasian populations,[24, 34–37] with disproportionately lower rates among Blacks and Hispanics,[23, 24, 37] consistent with our results among Blacks and Spanish-speaking Hispanics. However, English-speaking Hispanics and NHW had similar testing rates which may reflect acculturation of Hispanics over generations. Black women in our study were not recent immigrants and did not have a language barrier, yet their testing rates were the lowest demonstrating a concerning health disparity that requires focused attention. This is particularly alarming given that limited studies among high risk Hispanics[38–41] and Blacks[42] suggest high interest in these services once it is explained to them.

Reasons for lower testing rates among Blacks and Hispanics include both lower awareness about genetic testing[21] and access to cancer genetics experts,[43] geographic barriers,[44] language barriers,[45] and socioeconomic factors such as insurance, education and income.[46] In fact, the presence of private insurance had a direct impact on both genetic testing discussion and receipt of testing in the path model (Figure 3). Based on our own clinical experience this is not surprising because private insurers tend to be more likely to cover genetic testing than Medicaid. Additionally, a genetic test discussion may not even occur if testing is not perceived to be feasible by patients or providers, as might be the case if the patient is uninsured or on Medicaid. In our study, even after controlling for socioeconomic factors, Blacks were less likely to be tested but the single strongest predictor was provider discussion of genetic testing. Consequently, in addition to patient-level factors, provider and system level factors may contribute to suboptimal testing rates among minorities. In particular, multiple studies demonstrate the importance of healthcare provider recommendations in receipt of genetic testing, with lack of physician referral amongst the most highly cited barriers to testing among BC survivors. [23, 35, 47–50] Our findings that healthcare provider discussion of testing was the strongest predictor for receipt of *BRCA*

testing with lowest rates of both testing discussion and testing receipt among Blacks, is consistent with prior studies. Although not explored through our study, other potential explanations for observed differences include provider characteristics and distribution, as well as variability in clinical practice situations, which should be explored further through future efforts. Ultimately, our findings are concerning and suggest the need for the development of multi-level interventions targeted at both the patient and provider level in order to successfully address the widening disparities due to genomic advances.

The current study has several strengths including the first population-based design to systematically compare cancer risk management practices among *BRCA* carriers drawn from an ethnically and racially diverse sample of BC survivors treated across multiple settings, enhancing the generalizability of our findings. Furthermore, our estimates of provider discussion and genetic testing across diverse populations provides updated and novel data, compared to prior efforts with limited minority representation, non-population based sampling, or sampling frame of women diagnosed before 2008. [23, 35, 47–50] Furthermore, *BRCA* testing confirmation in over 72% of all cases further strengthens the accuracy and validity of our observations.

Despite these strengths, there remain some limitations including our inability to fully determine reasons for the observed differences in uptake of cancer risk management options and testing rates across populations. Furthermore, although participants were diagnosed within the same 4 years and eligibility criteria were the same, the Blacks and non-Blacks were recruited under separate protocols. However, time since diagnosis and age at diagnosis (or age at the time of the survey) were included in the models in order to minimize bias. Furthermore, our study is cross-sectional and represents a single snapshot in time, thus longitudinal follow-up is critical to determine whether these disparities persist or widen. As well, given the time between diagnosis and recruitment, there is potential for recall bias. Moreover, our sample size of carriers was limited, given that they represented a subset drawn from a much larger unselected population of BC survivors. Nevertheless, we observed clear differences in uptake of RRSO and RRM among Black carriers, which requires confirmation and additional longitudinal follow-up. Additionally, survey completion rates across racial subgroups was below 30% which may lead to selection bias, although the study population was comparable to the source population based on available clinical and demographic variables. As well, the sample was confined to Florida, thus may not be generalizable to other parts of the country where clinical practices may vary. Finally, all participants were diagnosed prior to a number of practice changing events that occurred around 2013 and beyond, including: plummeting sequencing costs due to technological advances in conjunction with the fall of the *BRCA* patent, implementation of the Affordable Care Act, and celebrity disclosures.[51, 52] To determine if these changes impacted populations with existing health disparities, more recent studies across ethnically and racially diverse populations of high risk patients are needed, as was recently identified as a research gap by the US Preventive Services Task Force (USPSTF).[53]

Ultimately, it is critical to better understand the reasons for the lower uptake of cancer risk management options among Black *BRCA* carriers, in order to develop interventions and assure access to preventive care. In this regard, coverage for genetic testing does not equate

to coverage for preventive care, which is essential to improve health outcomes.[54] Consequently, variations in preventive services coverage may exacerbate health disparities without policies to ensure equitable access to these services. Given that *BRCA* testing and cancer risk management are choices, it remains imperative to identify and discuss genetic testing with high risk patients across all populations, communicate the information in a culturally congruent and understandable way, and ensure access to testing and follow-up care regardless of socioeconomic factors.

In summary, our study is the first to demonstrate differences in cancer risk management across Blacks, Hispanics and NHW recruited through population-based efforts. The lower RRSO rates observed among Black *BRCA* carriers are particularly concerning given that most ovarian cancers are diagnosed at a later stage without reliable means for early detection. Furthermore, our findings demonstrate that healthcare provider discussion was the strongest predictor of testing. Taken together, the underlying etiology of differences observed in testing rates and follow-up care require further study to identify facilitators and barriers such as psychological, cultural and geographic factors. In addition to patient-specific factors, provider and system-level factors must be examined to develop solutions to narrow existing health disparities in gene-based care. Ultimately, multi-level interventions are needed to reduce the growing healthcare disparities in clinical cancer genetics.

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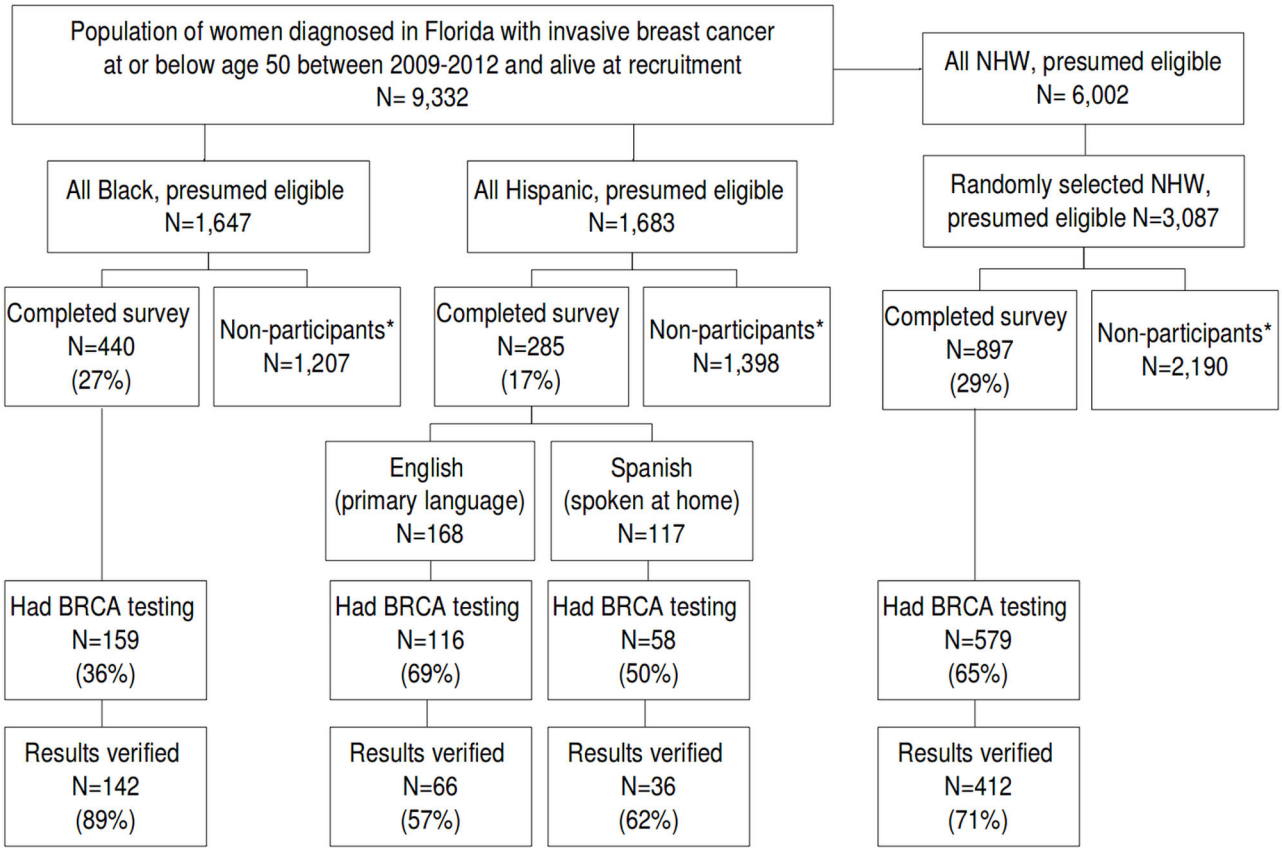

Figure 1.

Recruitment from the Florida cancer registry and participants with prior *BRCA* testing and results verification

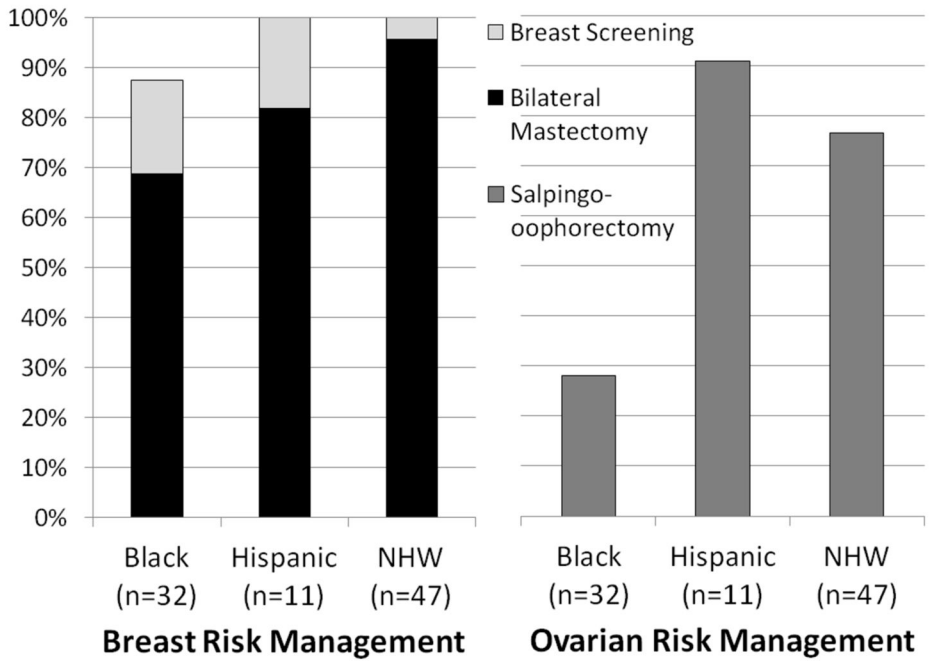

Figure 2.
Uptake of Risk Management Options among *BRCA* Mutation Carriers

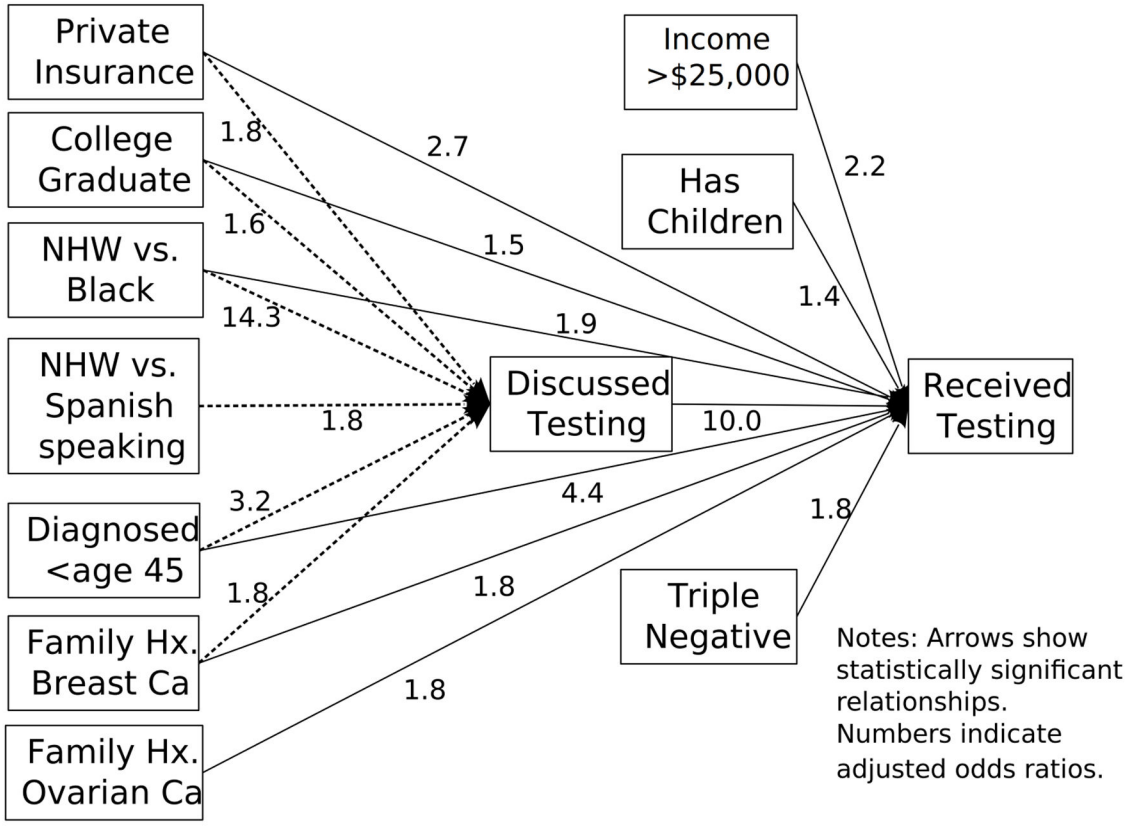

Figure 3.
Path model to demonstrate factors associated with healthcare provider discussion and subsequent receipt of *BRCA* testing

Table 1

Clinical and demographic comparisons between racial/ethnic groups

	Black N=440		English- speaking Hispanic N=168		Spanish- speaking Hispanic N=117		Non-Hispanic white N=897		
Characteristics	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**	***P***
Previous genetic testing									
No	281	63.9%	50	29.8%	59	50.4%	317	35.3%	<.0001
Yes	159	36.1%	118	70.2%	58	49.6%	580	64.7%	
Referred for genetic testing									
No	276	62.7%	24	14.3%	35	29.9%	126	14.1%	<.0001
Yes	164	37.3%	144	85.7%	82	70.1%	769	85.7%	
Unknown	-	-	-	-	-	-	2	0.2%	
Has children									
No	54	12.3%	54	32.1%	50	42.7%	263	29.3%	<.0001
Yes	386	87.7%	110	65.5%	64	54.7%	611	68.1%	
Unknown	-	-	4	2.4%	3	2.6%	23	2.6%	
Married or cohabiting									
No	262	59.55%	56	33.3%	37	31.6%	253	28.2%	<.0001
Yes	178	40.45%	112	66.7%	80	68.4%	644	71.8%	
Triple Negative									
No	300	68.2%	128	76.2%	88	75.2%	696	77.6%	<.0001
Yes	101	22.9%	21	12.5%	9	7.7%	119	13.3%	
Unknown	39	8.9%	19	11.3%	20	17.1%	82	9.1%	
Diagnosed ≤ age 45									
No	154	35.0%	76	45.2%	65	55.6%	465	51.8%	<.0001
Yes	286	65.0%	92	54.8%	52	44.4%	432	48.2%	
Income ≥ 25k									
No	154	35.0%	33	19.6%	48	41.0%	80	8.9%	<.0001
Yes	256	58.2%	126	75.0%	60	51.3%	754	84.1%	
Unknown	30	6.8%	9	5.4%	9	7.7%	63	7.0%	
College education									
No	263	59.8%	72	42.9%	65	55.6%	391	43.6%	<.0001

	Black N=440		English- speaking Hispanic N=168		Spanish- speaking Hispanic N=117		Non-Hispanic white N=897		
Characteristics	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**	***P***
Yes	175	39.8%	95	56.5%	52	44.4%	504	56.2%	
Unknown	2	0.4%	1	0.6%	-	-	2	0.2%	
Family history of breast cancer									
No	193	43.9%	85	50.6%	61	52.1%	396	44.15%	0.175
Yes	247	56.1%	83	49.4%	56	47.9%	501	55.85%	
Family history of ovarian cancer									
No	381	86.6%	150	89.3%	107	91.45%	795	88.6%	0.453
Yes	59	13.4%	18	10.7%	10	8.55%	102	11.4%	
Private insurance									
No	172	39.1%	38	22.6%	59	50.4%	142	15.8%	<.0001
Yes	255	57.95%	130	77.4%	58	49.6%	754	84.1%	
Unknown	13	2.95%	-	-	-	-	1	0.1%	
Median years from diagnosis to survey (range)	1 (0 – 4)		4 (0 – 6)		4 (2 – 6)		4 (0 – 6)		<.0001

Table 2

Results of multiple logistic regression showing associations with healthcare provider discussion of genetic testing and receipt of genetic testing

	Discussed Genetic Testing			Underwent Genetic Testing		
	OR	**95% CI**	***P***	**OR**	**95% CI**	***P***
Race group						
Black vs. NHW	0.06	0.04 – 0.10	<.0001	0.18	0.11 – 0.29	<.0001
English-speaking Hispanic vs. NHW	1.08	0.60 – 1.94	.80	1.52	0.96 – 2.39	.07
Spanish-speaking Hispanic vs. NHW	0.54	0.30 – 0.96	.04	1.07	0.62 – 1.83	.82
Has children						
Yes vs. No	1.38	0.96 – 1.98	.08	1.51	1.11 – 2.05	.01
Married or cohabiting						
Yes vs. No	0.87	0.63 – 1.20	.39	0.88	0.66 – 1.17	.37
Triple negative						
Yes vs. No	1.19	0.81 – 1.76	.37	1.74	1.22 – 2.48	.002
Diagnosed ≤ age 45						
Yes vs. No	3.16	2.28 – 4.38	<.0001	5.17	3.89 – 6.87	<.0001
Income ≥ 25k						
Yes vs. No	1.52	1.00 – 2.30	.05	2.27	1.54 – 3.37	<.0001
College graduate						
Yes vs. No	1.63	1.19 – 2.23	.002	1.71	1.31 – 2.24	<.0001
Family history of breast cancer						
Yes vs. No	1.76	1.31 – 2.38	.0002	1.98	1.53 – 2.57	<.0001
Family history of ovarian cancer						
Yes vs. No	1.35	0.85 – 2.15	.20	1.87	1.24 – 2.81	.003
Private insurance						
Yes vs. No	1.79	1.23 – 2.59	.002	2.88	2.04 – 4.07	<.0001
Years from diagnosis to survey (per 1 year increase)	0.97	0.84 – 1.11	.65	0.91	0.81 – 1.02	.10