**BRCA1/2 testing and cancer risk management in underserved women at a public hospital**

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**Background and objective:** Genetic test uptake and cancer risk management have been understudied in medically underserved populations. Study aims were to quantify rates of BRCA1/2 genetic testing and evidence-based cancer risk management (ie, prophylactic surgeries and surveillance practices) in women who were seen for breast and ovarian cancer genetic counseling in a public, safety net health system.

**Methods:** We conducted a retrospective medical record abstraction of 195 women who presented for breast or ovarian genetic counseling within a 2-year period (2008-2009) at Parkland Health & Hospital System in Dallas, Texas.

**Results:** The identified women represented a racially and ethnically diverse population: 48% Hispanic, 37% non-Hispanic black, 12% non-Hispanic white, and 3% Asian. Among the 158 women who were medically eligible for genetic testing, 134 (84.8%) received BRCA1/2 results, with most tests funded through a financial assistance program. In all, 29 women (22%) tested positive for BRCA1/2 mutations. Financial and funding barriers were identified for 20 of the untested women. Among the identified high-risk women (mutation carriers, selected variants, and noncarriers with pretest BRCAPRO scores ≥ 30), 26% had prophylactic breast surgeries and 33% had prophylactic ovarian surgeries within the follow-up period averaging 35 months. Of those who opted for surveillance, 71% had at least 1 mammogram or MRI and 38% had CA-125 tests. Trends indicated lower rates of all risk management behaviors, except for mammogram or MRI, among non-Hispanic black women.

**Conclusions:** Within this racially and ethnically diverse sample, BRCA1/2 test uptake was high, but financial barriers were identified for nontested women. The rates of breast cancer risk management were generally comparable with other studies, but risk management for ovarian cancer was limited, especially among non-Hispanic black women. The reasons for these apparent disparities should be further explored.

Emerging evidence suggests that racial, ethnic, and economic disparities occur in genetic testing and cancer risk management,1-4 but data are sparse and many questions remain. In particular, genetic testing and cancer risk management have been understudied in medically underserved populations. For breast and ovarian cancer susceptibility, most insurers cover BRCA1/2 testing and Myriad Genetics Inc has a full-cost reimbursement program for the poor and uninsured. However, low-income, uninsured individuals may not be able to obtain test coverage from Myriad Genetics if they do not meet the income or documentation requirements of the program. The only option for these patients may be out-of-pocket funding, a situation with significant cost barriers (more than $3,400 for full sequencing). Among those who are tested, underinsured women may also face access barriers to risk-reducing procedures, including prophylactic surgeries and cancer surveillance. To address these issues, we conducted a retrospective analysis of genetic testing uptake and breast and ovarian cancer risk management in racially and ethnically diverse and underinsured women who sought cancer genetic counseling through a safety net hospital system. The aims of the study were to quantify rates of BRCA1/2 genetic testing and evidence-based cancer risk management (ie, prophylactic surgeries, surveil-
Discoveries of the cancer susceptibility genes BRCA1 and BRCA2 ushered in an era in which genetic counseling, genetic testing, and cancer risk management are important components of oncology care. Germline mutations in the BRCA1/2 genes are associated with significantly increased lifetime risks of breast (up to 85%) and ovarian (up to 45%) cancers for women. For women who are BRCA1/2 mutation carriers or at high risk based on family or personal cancer history, there is a demonstrated risk-reduction impact of prophylactic surgeries and multiple image modalities for cancer surveillance. For example, among high-risk women, prophylactic mastectomy is associated with a 90% reduction in the risk of breast cancer, and bilateral salpingo-oophorectomy is associated with an 85% reduction in the risk of ovarian cancer risk. The addition of breast ultrasound and MRI to standard mammography and clinical breast exam increases breast cancer detection rates from 45% to 95% in BRCA1 mutation carriers.

Despite strong evidence for these risk-reducing procedures, little is known about genetic test uptake and cancer risk management in racial and ethnic minorities and in underinsured populations. Although a systematic review of BRCA1/2 genetic testing uptake found a mean rate of 59% (range, 25%-96%) across 18 patient groups, most samples were primarily non-Hispanic white and testing was covered by insurance, research, or institutional funds. A handful of studies have described lower genetic testing rates for African American women, but these studies also included funding for test costs. There is little information about genetic testing uptake among Hispanic populations. A few studies have noted perceived disadvantages of cancer genetic testing and language and/or acculturation barriers, but we could find limited information about actual BRCA1 uptake in Hispanic populations. One study that provided grant-funded BRCA1 testing for a predominantly Hispanic population reported a test uptake of 62% in an index sample of 77 women, and 100% uptake among 23 family members of tested women. In regard to underinsured populations tested outside of the context of research- or institutional-funded testing, one study reported a test uptake of 41.2% in their population without insurance coverage for testing (17 patients), but the small size and lack of supplemental information did not allow for extrapolation in this subset.

A review of 37 cancer risk management studies highlighted a less-than-optimal use of mammography in women who had undergone BRCA1/2 testing, along with variable rates of prophylactic surgeries. A more recent report examined longer-term use of these risk-reduction strategies among tested women and noted high rates of mammography adherence (mean follow-up, 5.3 years; 82% of unaffected patients; 92% of affected patients) and screening MRI (46% and 51%, respectively) among carriers. In addition, 37% of eligible mutation carriers reported posttest prophylactic mastectomy, and 65% reported posttest prophylactic oophorectomy. Again, however, ethnic minorities and underinsured populations were generally underrepresented in that study (94% of the population in was classified as white). Another study investigated risk reduction behaviors in an African American kindred following BRCA1 testing, noting low uptake of prophylactic surgeries; however, small numbers limit interpretation of findings in this report. Thus, although cancer genetic uptake and cancer risk management have been relatively well studied, there is a significant gap in knowledge about medically underserved populations. Few investigators have addressed racial and ethnic disparities among underinsured populations who do not have access to research- or institutional-funded testing. Here, we investigate genetic testing uptake and breast and ovarian cancer risk management among ethnically diverse and underinsured women who sought cancer genetic counseling through a safety net hospital system.

Materials and methods

Study population

The study population included women who presented at Parkland Health and Hospital System (PHHS) in Dallas, Texas, for breast and ovarian cancer genetic counseling from January 2008 to December 2009. Parkland is Dallas County’s sole safety net hospital and health system responsible for providing care for about 1 million uninsured and underinsured county residents. It also serves as a primary teaching hospital for the University of Texas Southwestern Medical Center. County residents who are uninsured and ineligible for Medicare or Medicaid may qualify for Parkland HEALTHplus, a program for services received through Parkland Memorial Hospital and its affiliated primary and specialty clinics. Other Parkland patients may receive limited funding from other charity payors or local agencies.

Parkland Cancer Genetics Clinic

In January 2008, a monthly, onsite cancer genetics clinic was started at Parkland Hospital and staffed by cancer genetic counselors affiliated with UT Southwestern’s Harold C. Simmons Cancer Center. Genetic counseling is offered free of charge at the clinic, but patients are responsible for genetic testing costs. Although BRCA1 testing is covered under most private insurance plans,
Medicare, and Medicaid for eligible individuals, it is not a covered benefit under the Parkland HEALTHplus program or other known charity payors for the county’s residents. Myriad Genetics, which performs all BRCA gene testing in the United States, offers a financial hardship program that covers testing costs for medically eligible patients who are uninsured and who meet certain financial criteria. The company’s medical criteria are consistent with the National Comprehensive Cancer Network (NCCN) criteria for BRCA gene testing. During the period covered by this analysis (2008-2009), Myriad’s financial criterion for testing was 1.5 times the Federal poverty level. (It was increased to twice the Federal Poverty level in 2011).

Referrals to Parkland’s Cancer Genetics Clinic were primarily made by Parkland medical and surgical oncologists. A handful of patients were referred by primary care teams or they self-referred. The genetic counseling process at Parkland, detailed elsewhere, uses the CancerGene system, to collect information about patient and family history and generate relative risk calculations derived from BRCAPRO, a Bayesian risk model, and Myriad prevalence tables. Patients are counseled about their relative risk of cancer and genetic testing options based on these sources of information. Those who are identified as having a BRCA1 or BRCA2 mutation, or who have a family history consistent with hereditary breast or ovarian cancer syndrome (BRCAPRO score ≥ 30), are referred by a cancer genetic counselor to Parkland’s High Risk Breast Clinic which, to ensure continuity of care, is staffed by a single breast surgical oncologist. At this appointment, high-risk surveillance and prophylactic surgery options are discussed for both breast and ovarian cancer risk management. The Parkland HEALTHplus program covers costs of prophylactic surgeries and enhanced screening for high-risk women, as do Medicare, Medicaid, and most private insurers.

The High Risk Clinic’s breast surgical oncologist coordinates care among multiple indicated services, including radiology, gynecology-oncology, and reconstructive surgery. Patients who choose prophylactic mastectomies are referred to plastic surgery to consider options for breast reconstruction, and then the procedure is coordinated with the surgical oncology and plastic and reconstructive surgery teams. For women who choose surveillance, alternating diagnostic mammogram and breast MRI are offered every 6 months, along with clinical breast examinations. For ovarian cancer risk reduction, patients are referred to the gynecology oncology service for annual pelvic examination, transvaginal ultrasound, and CA-125 levels. Prophylactic bilateral salpingooophorectomy is recommended at 35 years of age, or once childbearing is complete, for all women with BRCA1 and BRCA2 mutations, or if a strong family history of ovarian cancer exists. If a woman declines surgery, heightened surveillance is continued.

Data abstraction process
Patient characteristics, genetic testing uptake and funding thereof, and cancer risk management were abstracted retrospectively from the Parkland electronic medical charts and the Cancer Genetics database. Data abstractors included research associates trained by the principal investigator (HH) and co-investigators (LR, AM). A surgical oncology fellow (JM) provided consult for collecting surgical and surveillance data. Collected demographic variables included race, ethnicity, age, and marital status. Clinical data included personal and family histories of breast and ovarian cancer (first- and second-degree relatives), previous breast and ovarian surgeries, and pre-evaluation BRCAPRO scores.

Statistical methods
Descriptive data are summarized by means, standard deviations, cell counts, and percentages. Where sample size allowed, chi-square and t-test analyses identified statistical differences in test uptake and cancer risk management decisions associated with demographic factors (age, race and ethnicity, marital status). In comparisons of dichotomous variables with cell sizes < 5, no statistical comparisons were performed.

Results
We identified 195 women who were seen for breast and ovarian cancer genetic counseling at the Parkland cancer genetics clinic in 2008 and 2009. Mean age at time of consultation was 43.3 years (SD, 10.38 years; range, 20-76). Table 1 provides other demographic and clinical characteristics of this sample.

BRCA1/2 genetic test uptake and funding source
Of the 195 women who were seen for breast and ovarian genetic counseling, 37 (19.0%) were deemed medically ineligible for BRCA1/2 testing (based on personal and family cancer history criteria of the clinic, the patient’s insurance company, Medicaid or Medicare, or Myriad Genetics criteria). Among the 158 medically eligible women, 134 (84.8%) received BRCA1/2 results either through full sequence testing (120 patients), single-mutation testing (13 patients), or determination of obligate carrier status based on a child’s test result (1 patient). Of note is that all 31 women with BRCAPRO scores ≥ 30 received BRCA1/2 test results. Most of the women who were tested (102; 76.7%) were uninsured for BRCA test coverage and received funding from the Myriad Ge-
netics program. Other funding sources included private insurance (6 patients; 4.5%), Medicare (8; 6.0%), Medicaid (9; 6.8%), out of pocket (3; 2.3%), and a research study at Baylor Medical Center in Dallas (5; 3.8%).

Non-Hispanic black women had the lowest rates of test uptake and result notification compared with the other racial and ethnic groups (Table 2), but the difference fell short of statistical significance. In addition, marital status (married/partnered, 84.5%, vs separated/unmarried, 85.3%) was not significantly associated with BRCA1/2 test uptake, and there was no significant difference in age between women who were tested (mean, 42.7 years) and those who were untested (mean, 44.5 years).

BRCA1/2 genetic test results

Among the 134 women who received BRCA1/2 test results, 29 (21.6%) had deleterious mutations (22 in BRCA1; 7 in BRCA2). In addition, 6 (4.5%) women had variants of unknown significance, and 1 woman (0.7%) had a polymorphism. No BRCA1 mutation was found in the remaining 98 (73.1%) women. Of the 29 BRCA1 or BRCA2 carriers, 21 (72.4%) had a history of previous breast and/or ovarian cancer.

Information about nontested women

Among the 158 medically eligible women, 24 (15.2%) did not have BRCA1/2 testing. Four of these women declined testing. The remaining 20 patients were uninsured (or had coverage that did not include BRCA1/2 testing) and faced barriers in funding that precluded their testing. Twelve of the 20 did not meet the financial criteria for the Myriad Genetic Financial Assistance Program, and the other 8 started the process with Myriad but had incomplete or missing income documents.

Decisions about cancer risk management

We extracted data focused on prophylactic surgeries and cancer surveillance for the 39 women who were counseled as “high risk,” including, BRCA1/2 carriers (29 patients), selected variants (2), and noncarrier women who had no known family mutation yet had pretest BRCAPRO scores of 30 or more (8). The time between genetic evaluation and data abstraction for these women averaged 35 months (range, 22–43 months). At time of genetic

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**TABLE 1** Patient demographic and clinical characteristics<sup>a</sup>

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>No. of patients (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Race/ethnicity</strong></td>
<td></td>
</tr>
<tr>
<td>Hispanic (any race)</td>
<td>93 (47.7)</td>
</tr>
<tr>
<td>Non-Hispanic white</td>
<td>24 (12.3)</td>
</tr>
<tr>
<td>Non-Hispanic black</td>
<td>73 (37.4)</td>
</tr>
<tr>
<td>Asian</td>
<td>5 (2.6)</td>
</tr>
<tr>
<td><strong>Marital status</strong></td>
<td></td>
</tr>
<tr>
<td>Married/partnered</td>
<td>70 (35.9)</td>
</tr>
<tr>
<td>Separated</td>
<td>18 (9.2)</td>
</tr>
<tr>
<td>Never married/divorced</td>
<td>101 (51.8)</td>
</tr>
<tr>
<td>Unknown</td>
<td>6 (3.1)</td>
</tr>
<tr>
<td><strong>Diagnosis of breast cancer(s) prior to genetic counseling</strong></td>
<td></td>
</tr>
<tr>
<td>Yes, treatment complete</td>
<td>48 (24.6)</td>
</tr>
<tr>
<td>Yes, treatment ongoing/upcoming</td>
<td>97 (49.7)</td>
</tr>
<tr>
<td>No</td>
<td>50 (25.6)</td>
</tr>
<tr>
<td><strong>Diagnosis of ovarian cancer prior to genetic counseling</strong></td>
<td></td>
</tr>
<tr>
<td>Yes, treatment complete</td>
<td>4 (2.1)</td>
</tr>
<tr>
<td>Yes, treatment ongoing</td>
<td>4 (2.1)</td>
</tr>
<tr>
<td>No</td>
<td>187 (95.9)</td>
</tr>
<tr>
<td><strong>Family history of breast cancer</strong></td>
<td></td>
</tr>
<tr>
<td>(1st, 2nd degree)</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>106 (54.4)</td>
</tr>
<tr>
<td>No</td>
<td>89 (45.6)</td>
</tr>
<tr>
<td><strong>Family history of ovarian cancer</strong></td>
<td></td>
</tr>
<tr>
<td>(1st, 2nd degree)</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>42 (21.5)</td>
</tr>
<tr>
<td>No</td>
<td>153 (78.5)</td>
</tr>
<tr>
<td><strong>BRCAPRO scores</strong></td>
<td></td>
</tr>
<tr>
<td>30 and higher</td>
<td>31 (15.9)</td>
</tr>
<tr>
<td>Under 30</td>
<td>156 (80.0)</td>
</tr>
<tr>
<td>Insufficient information to calculate</td>
<td>8 (4.1)</td>
</tr>
</tbody>
</table>

<sup>a</sup>For 195 women seen for breast or ovarian cancer genetic counseling during 2008-2009.

**TABLE 2** BRCA test uptake by race and ethnicity among medically eligible women<sup>a</sup>

<table>
<thead>
<tr>
<th>Race/ethnicity</th>
<th>Tested No. of patients (%)&lt;sup&gt;b&lt;/sup&gt;</th>
<th>Not tested No. of patients (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hispanic (any race)</td>
<td>69 (84.3)</td>
<td>10 (12.7)</td>
</tr>
<tr>
<td>Non-Hispanic white</td>
<td>15 (83.3)</td>
<td>3 (16.7)</td>
</tr>
<tr>
<td>Non-Hispanic black</td>
<td>45 (80.4)</td>
<td>11 (19.6)</td>
</tr>
<tr>
<td>Asian</td>
<td>5 (100.0)</td>
<td>0 (0)</td>
</tr>
</tbody>
</table>

<sup>a</sup>Total number of women, 158 (134 tested, 24 not tested); <sup>b</sup>This group of 134 patients includes 1 woman determined to be an obligate carrier based on a child’s test result.

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<sup>1</sup>One of these variant results was later reclassified as a deleterious mutation. This patient was counseled as “high risk” throughout the entire process.
evaluation, 38 of the 39 of the high-risk women had at least 1 breast (8 had prior single, complete mastectomies), and 36 had intact ovaries.

**Prophylactic surgeries among high-risk women**

During the time between genetic evaluation and data abstraction, 10 out of the 38 eligible high-risk women (26.3%) had prophylactic breast surgery, including 5 who opted to have the contralateral breast removed as part of their primary breast cancer surgery, and 5 whose prophylactic mastectomies were not associated with treatment surgeries. Most of the prophylactic breast surgeries (9 women) were seen among mutation carriers; overall, 9 out of the 28 eligible mutation carriers (ie, with at least 1 breast; 32.1%) had prophylactic breast surgery. One of the 2 women (50%) with high-risk variants had prophylactic breast surgery, and none of the 8 (0%) noncarrier high-risk women elected prophylactic breast surgery. Younger women were marginally more likely to have prophylactic breast surgery, compared with older women (mean, 36.3 vs 42.8 years; \( P = .07 \)). Cell size considerations did not allow statistical analyses of prophylactic surgery decisions based on the other demographic factors. However, descriptive data indicated that among 38 eligible women, only 11.1% of non-Hispanic black women had prophylactic breast surgery, compared with 31.0% of women from the other race or ethnicity categories.

Among the 36 high-risk women who had intact ovaries, 12 (33.3%) had prophylactic ovarian surgery within the period of data abstraction. All 12 women were BRCA1/2 mutation carriers; thus, 12 out of the 26 eligible carriers (ie, those with intact ovaries prior to genetic testing; 46.2%) had prophylactic oophorectomy. There was no significant difference in surgery uptake based on age (surgery: mean, 40.7 years vs no surgery: mean, 40.3 years). Although cell sizes did not allow statistical testing of other demographics, descriptive information showed that married women had higher rates of oophorectomy (53.3%), compared with unmarried women (22.1%); and non-Hispanic black women had lower rates of oophorectomy (20.0%), compared with women of other races (38.5%).

**Surveillance practices**

We investigated breast surveillance practices for the 28 eligible high-risk women who did not have prophylactic mastectomies, and CA-125 testing for the 24 high-risk women who did not have prophylactic oophorectomies. Given the time between genetic evaluation and data abstraction (average of 35 months), all of these eligible women should have had at least 1 breast surveillance (mammogram or MRI) and 1 CA-125 test, per counseled guidelines. Overall, 20 out of 28 women (71.4%) had at least 1 mammogram or MRI during the period between genetic evaluation and data abstraction. Specifically, 15 out of 19 eligible carriers (78.9%), 1 out of 1 eligible variant, and 4 out of 8 high-risk noncarriers (50.0%), had mammograms or MRIs. Women who received mammograms or MRI were significantly older (mean, 45.2 years) than women who did not receive them (mean 36.8 years; \( P < .05 \)). Given the high overall uptake of mammography and small cell sizes, statistical comparisons based on other demographic factors were not performed. Descriptive percentages showed higher rates of mammography and MRI usage in non-Hispanic back women (87.5%) than in women of other races or ethnicities (65.0%), and higher rates among married or partnered women (90.0%), compared with unmarried women (73.3%). Of the 8 women who did not have mammograms or MRIs, 2 (1 carrier and 1 noncarrier) are known to have died during cancer treatment between the time of genetic risk evaluation and data abstraction, and the other 6 (3 carriers and 3 noncarriers; 21.4% of the breast surveillance-eligible total) were considered “nonadherent” based on appointment no-shows, returned correspondence, or otherwise lost to follow-up.

Of the 24 high-risk women with intact ovaries, 9 (37.5%) had CA-125 tests. Specifically, 6 out of 14 carriers (42.9%), 1 out of 2 (50%) variants, and 2 out of 8 (25.0%) noncarriers, had CA-125 tests. There was no significant difference in age between those who had CA-125 tests and those who did not (mean, 42.2 years and 39.2 years, respectively). Although cell sizes precluded statistical analysis, descriptive data showed that none of the non–Hispanic black women received CA-125 tests, whereas 56.3% of the other women did. Among married or partnered women, 57.1% received CA-125 tests, compared with 33.3% of unmarried women. Of the 15 eligible women who did not get CA-125 tests, 1 (noncarrier) died between the time of genetic evaluation and data abstraction, and the other 14 (58.3% of eligible population) were considered “nonadherent” to CA-125 recommendations.

**Discussion**

BRCA1 genetic testing and cancer risk management are associated with significant benefits in cancer risk reduction. Despite this promise, there have been few investigations of testing, surgery, and surveillance decisions among underserved populations. As one of the few cancer genetics clinics serving public, safety net hospital systems, the Parkland cancer genetics clinic provided a unique opportunity to evaluate cancer genetic testing and risk management behaviors among an ethnically diverse and underinsured population.
Genetic testing uptake
The 84.8% of medically eligible women who received BRCA test results is somewhat higher than many other published reports (including a mean rate of 59% across 14 studies\(^{15}\)). Non-Hispanic black women had the lowest rates of test uptake among the medically eligible sample, but the difference across racial and ethnic groups was not statistically significant. We also found no other demographic (eg, age, marital status) differences between medically eligible tested and nontested women.

Impact of test cost in uninsured women
The majority of women who received BRCA testing (76%) were uninsured and received test funding through the Myriad Genetics assistance program. Without this program, these high-risk patients would have been required to pay more than $3,400 out of pocket for the test, and uptake would likely have been significantly lower. Given that 29 gene mutations (plus 1 variant later reclassified as a deleterious mutation) were found during the testing process, this significant cost barrier to testing could have resulted in higher morbidity and mortality for many women. Despite this funding option, a minority of untested, uninsured women (20) were medically eligible (and did not overtly decline testing) but may have “fallen through the cracks” of financial eligibility. These women either had incomes that were too low to meet the Myriad criteria (150% above poverty level at the time) or were unable to furnish the required documents needed to verify income levels. In such cases, these uninsured women were without testing options if they could not pay out of pocket and were required to make risk management decisions without information about BRCA status. Financial barriers also delayed testing for a small number of women; we noted at least 4 women whose tests were eventually covered by Myriad but whose testing was delayed because of initial financial ineligibility. Overall, our results indicate that among underinsured populations, financial barriers to BRCA testing are significant. Within our clinic, recent grant funding now covers test costs for uninsured high-risk women who are financially ineligible for Myriad coverage. However, such measures are temporary and do not address the long-term issues associated with BRCA coverage in underinsured populations.

Cancer management decisions
Breast surgery and surveillance. Our investigation also focused on cancer risk management behavior among the high-risk women in the sample (ie, mutation carriers, high-risk variants, and noncarriers with pretest BRCAPRO scores ≥ 30). Because high-risk, uninsured women received financial coverage for surgeries and enhanced surveillance under the Parkland HEALTHplus program, cost was unlikely to be a barrier to cancer risk management. Within a follow-up period that averaged almost 3 years after genetic testing, 26% of the overall high-risk patient population (including 32% of mutation carriers) had prophylactic mastectomies. Half of those patients had prophylactic surgery of 1 breast in conjunction with treatment surgery for the second breast, a result not surprising given that almost half of patients who presented to the Cancer Genetics clinic were in the process of treatment or treatment decision-making. These prophylactic mastectomy rates in our sample are comparable with those in other US studies with similar follow-up windows.\(^{23,30}\) We did note younger age as a predictor of prophylactic breast surgery, along with lower levels of uptake (although not statistically tested) among non-Hispanic black women. Among women who did not have prophylactic mastectomies, 71% received at least 1 mammogram or MRI during the follow-up period (79% of carriers), a number slightly lower, but generally comparable with other studies.\(^{23,31}\) In our sample, older women were more likely to have a mammogram or MRI, and although we did not do a statistical comparison with other groups, non-Hispanic black women had generally high rates of mammography and MRI utilization. Therefore, despite a lower rate of prophylactic mastectomy, non-Hispanic black women in our sample had higher rates of adherence to breast surveillance recommendations.

Ovarian surgery and surveillance. Within our eligible sample (high-risk women with intact ovaries), 33% (including 46% of mutation carriers) had prophylactic oophorectomy. This total is lower than the 65% of carriers reported by Schwartz and colleagues,\(^{23}\) and with other studies with similar time frames of evaluation.\(^{32}\) One possibility for lower rates of oophorectomy are the differences in age and childbearing intentions within our sample. Given that one-third of the women in our sample who did not get prophylactic oophorectomies were under the age of 35 years, it is possible that a desire for more children delayed their decisions about surgery. Despite the low rate of prophylactic oophorectomies, only 38% of eligible patients with ovaries had at least 1 CA-125 test during the study period, a number that was much lower than expected given ovarian cancer risks in this population. One troubling finding was that none of the eligible non-Hispanic black women had a CA-125 test within the Parkland system. It is possible that a subset of these women had CA-125 testing outside of the system, but this has a low probability given Parkland’s sole safety net status within the county. Instead, this finding suggests
significant deficiencies within the referral process. Overall, lower rates of ovarian risk management may be a system continuity problem related to lack of a specific contact within relevant departments at Parkland. Unlike the case of breast cancer risk management, in which a dedicated breast surgeon is part of the cancer genetics team, ovarian management lacked a consistent stakeholder and was less coordinated, with some patients followed by a gynecologic oncologist and others followed in the general gynecology clinic. Since the time of the study we have identified a physician champion for this clinic who will coordinate the care of all the mutation carriers and other high-risk women.

**Conclusions**

Given that this was a first study of genetic testing and risk management behaviors among racially and ethnically diverse safety net patients, our findings are somewhat encouraging. BRCA1 test uptake was high, although financial barriers were identified within the population. Among high-risk women, breast cancer risk management behaviors were generally comparable with those described in other populations. However, this was not the case for ovarian cancer risk management behaviors. Lower participation in prophylactic oophorectomy may be the result of young age and childbearing decisions, but participation in CA-125 testing is problematic and must be further explained and addressed. Also of concern is the trend toward lower participation by non-Hispanic black women in all risk management behaviors except mammography and MRI (in which participation was higher). The reasons for that seeming disparity, including cultural beliefs, mistrust of the medical system, and medical communication barriers should be further explored.

**Acknowledgments**

This study was supported by a grant to Dr. Hamann from the Simmons Cancer Center and American Cancer Society (ACS-IRG-02-196). The authors thank the staff and patients at Parkland Health and Hospital System for their assistance with this study. The authors also thank Maria Funes, Adam Loewen, Katharine McAllister, and Jay Morrow for their assistance in data collection and management. Simon Craddock Lee and Cassidy Cisneros provided helpful comments on drafts of this manuscript.

**References**