Examining Racial Differences in Utilization of Genetic Counseling Services in Hereditary Cancer Network Database

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Background: Genetic Cancer

- Hereditary Breast and Ovarian Cancer (HBOC)
  - Breast cancer risk: 46% - 71% in women and 2.8% in men
  - Ovarian cancer risk: 17% - 46%

- Lynch Syndrome
  - Colorectal cancer risk: 22% - 92%
  - Endometrial cancer risk: 20% - 70%
  - Ovarian cancer risk: 4% - 12%

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Meeting one or more of these criteria warrants further assessment and genetic testing and management

- Known Familial Mutation
- Ashkenazi Jewish
- Personal HX of Breast Cancer diagnosed at age 50 or younger
- Personal HX of Multiple Primary Breast Cancer
- Personal HX of Male Breast Cancer
- Personal HX of Triple Negative Cancer
- Personal HX of Ovarian, Prostate, or Pancreatic Cancer
- No personal HX but a significant family history
Michigan Cancer Surveillance Program: 15-Yr Annual Age-Adjusted Incidence Rates for Breast Cancer- Age 50 or Younger, by Race

Statistics provided by the Michigan Cancer Surveillance Program, September 2017

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Michigan Cancer Surveillance Program: 15-Yr Annual Age-Adjusted Mortality Rates for Breast Cancer - Age 50 or Younger, by Race

Statistics provided by the Michigan Cancer Surveillance Program, October 2016
Black women less likely to receive a physician recommendation for BRCA ½ testing\(^1\)
- Difference remained after adjusting for mutation risk

Black women diagnosed with breast cancer are less likely to receive genetic testing compared to White women \(^2\)
- Predictors of BRCA ½ testing uptake include being at high risk of mutation, understanding the benefits of testing, and having few financial and administrative barriers

Rates of risk reducing surgeries are lower among Black BRCA carriers compared to White and Hispanic carriers \(^3\)
- Also found discussion of genetic testing with a provider was 16 times less likely among Black women compared to White women.

- 5 year CDC Cooperative Agreement
- Long-term aim: to reduce mortality rates of hereditary cancers by overcoming barriers and advancing health system changes to promote cancer genomics best practices
- Surveillance Strategy: To develop and expand surveillance systems on hereditary cancers and use of cancer genomics best practices for Hereditary Breast and Ovarian Cancers (HBOC) and Lynch Syndrome (LS)
Clinical data collected on all **HBOC/BRCA-related** genetic counseling visits conducted by board-certified/eligible genetic specialist at 18 clinic locations across Michigan
- Starting in 2015, case definition increased to include LS-related visits
- Adults, age 18 or older
- Patient visits from 2008-Present

Data includes: Demographics, visit information, personal and family history of cancer, BRCA testing results, and cancer-related surgical procedures

Current analysis examines patients who self-identified as either White or Black for years 2008-2015
- Total Population = 20,275 (N=1,859 under new case definition)
- White Population= 16,569 (81.7%)
- Black Population= 1,502 (7.4%)
- Other Population= 2,204 (10.9%)
Racial Distribution: MI Overall Population vs Hereditary Cancer Network Database Patients Counseled

1 Other = Asian, American Indian/Alaska Native, Native Hawaiian/PI, Hispanic, Multi-racial
Initial Genetic Counseling Visits by Race: 2008-2015

Due to methodology changes that took place in 2014, estimates from 2014 and moving forward cannot be compared to estimates from 2013 and earlier.
Characteristics of Patients in Hereditary Cancer Network Database by Race: 2008-2015

- Average Age
  - Black: 49.3 years (Range 18 to 83)
  - White: 51.9 years (Range 18 to 94)
Characteristics of Patients in Hereditary Cancer Network Database by Race: 2008-2015

**Insurance Status**

<table>
<thead>
<tr>
<th></th>
<th>Medicaid ¹</th>
<th>Medicare</th>
<th>Private ¹</th>
<th>Uninsured</th>
<th>Unknown</th>
</tr>
</thead>
<tbody>
<tr>
<td>Black (N=1,502)</td>
<td>187 (12%)</td>
<td>181 (12%)</td>
<td>997 (66%)</td>
<td>17 (1%)</td>
<td>120 (9%)</td>
</tr>
<tr>
<td>White (N=16,569)</td>
<td>568 (3%)</td>
<td>2,567 (15%)</td>
<td>11,789 (71%)</td>
<td>142 (1%)</td>
<td>1,503 (10%)</td>
</tr>
</tbody>
</table>

¹ Statistically Significant at P value < 0.05

**Referring Provider**

<table>
<thead>
<tr>
<th></th>
<th>Internal Med ¹</th>
<th>Oncologist ¹</th>
<th>OB/GYN</th>
<th>Self ¹</th>
<th>Surgery</th>
<th>Other ²</th>
</tr>
</thead>
<tbody>
<tr>
<td>Black (N=1,502)</td>
<td>142 (9%)</td>
<td>455 (30%)</td>
<td>203 (14%)</td>
<td>50 (3%)</td>
<td>357 (24%)</td>
<td>242 (16%)</td>
</tr>
<tr>
<td>White (N=16,569)</td>
<td>1,069 (6%)</td>
<td>3,214 (19%)</td>
<td>2,323 (14%)</td>
<td>1,474 (9%)</td>
<td>3,984 (24%)</td>
<td>1,474 (19%)</td>
</tr>
</tbody>
</table>

¹ Statistically Significant at P value < 0.05

Missing data Black N= 53 (4%), White N=1,396 (9%)

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Counseled, Tested, and Received Positive Result by Race: 2008-2015

**White**
- Initial Visit: 16,552
- Genetic Testing Ordered: 10,274 (62%)
- At Least 1 Positive Result: 1,328 (13%)

**Black**
- Initial Visit: 1,501
- Genetic Testing Ordered: 783 (52%)
- At Least 1 Positive Result: 67 (9%)

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Genetic Test Type by Race: 2008-2015

All comparisons statistically significant at p-value < 0.05
Reasons Why Genetic Testing was not Pursued by Race

Black
N=719

- Unknown: 46%
- Chose not to Test: 8%
- Not a good Candidate: 22%
- Other \( ^{1,2} \): 8%
- Insurance Coverage \( ^2 \): 16%

White
N=6,280

- Unknown: 50%
- Not a good Candidate: 20%
- Other \( ^{1,2} \): 11%
- Chose not to Test: 8%
- Insurance Coverage \( ^2 \): 11%

\(^1\) Other includes: Patient previously tested, waiting to talk to relatives, concern about genetic discrimination, wants to test elsewhere.

\(^2\) Statistically significant at p-value < 0.05
### Initial Genetic Counseling Visits and Testing by Race and Gender

#### Initial Counseling Visits

<table>
<thead>
<tr>
<th></th>
<th>Black N (%)</th>
<th>White N (%)</th>
<th>Total N(%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>1,449 (97%)</td>
<td>15,487 (94%)</td>
<td>16,936 (94%)</td>
</tr>
<tr>
<td>Male</td>
<td>52 (3%)</td>
<td>1,065 (6%)</td>
<td>1,117 (6%)</td>
</tr>
<tr>
<td>Total</td>
<td>1,501 (100%)</td>
<td>16,552 (100%)</td>
<td>18,053 (100%)</td>
</tr>
</tbody>
</table>

#### Genetic Testing Ordered following Initial Visit

<table>
<thead>
<tr>
<th></th>
<th>Black N (%)</th>
<th>White N (%)</th>
<th>Total N(%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>753 (52%)</td>
<td>9,566 (62%)</td>
<td>10,319 (61%)</td>
</tr>
<tr>
<td>Male</td>
<td>29 (56%)</td>
<td>696 (65%)</td>
<td>725 (65%)</td>
</tr>
<tr>
<td>Total</td>
<td>782 (52%)</td>
<td>10,262 (62%)</td>
<td>11,044 (61%)</td>
</tr>
</tbody>
</table>
Genetic Counseling in Males by Race

- Age Adjusted Breast Cancer Incidence Rates for 2008-2013 in Males $^{1,2}$
  - Black: 2.64 / per 100,000
  - White: 1.36/ per 100,000

- Personal Cancer History

<table>
<thead>
<tr>
<th></th>
<th>Any Cancer $^2$</th>
<th>BRCA Related Cancer $^{2,3}$</th>
<th>Breast Cancer $^2$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Black</td>
<td>35 (67%)</td>
<td>25 (48%)</td>
<td>18 (35%)</td>
</tr>
<tr>
<td>White</td>
<td>518 (49%)</td>
<td>274 (26%)</td>
<td>127 (15%)</td>
</tr>
</tbody>
</table>

- Family Cancer History

<table>
<thead>
<tr>
<th></th>
<th>Known Familial Mutation $^2$</th>
<th>No Personal HX, Familial BRCA Related Cancer $^{2,4}$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Black</td>
<td>4 (8%)</td>
<td>20 (38%)</td>
</tr>
<tr>
<td>White</td>
<td>358 (34%)</td>
<td>686 (65%)</td>
</tr>
</tbody>
</table>

$^1$ Statistics provided by the Michigan Cancer Surveillance Program, September 2017
$^2$ Statistically significant at p-value < 0.05
$^3$ BRCA Related Cancer defined as Breast, Ovarian, Prostate or Pancreatic Cancer
$^4$ Abbreviation: HX=history
Select NCCN Guideline Criteria among Counseled Patients by Race: 2008-2015

Abbreviations: BC= Breast Cancer  OC=Ovarian Cancer
1 Statistically significant at P-Value < 0.05
2 BRCA Related Cancer defined as Breast, Ovarian, Prostate, and Pancreatic Cancer

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Summary of Major Findings

- Blacks are underrepresented in this genetic counseling database
- Statistically significant differences exist in genetic testing by race
  - Insurance coverage a barrier?
- Blacks were more likely to be younger and with a personal history of cancer
- Whites were more likely to have a known familial mutation or significant family history without having a personal history of cancer
  - Cascade Screening important to identify those without personal history
Limitations

- Not representative of all Genetic Counseling
  - 18 clinics represented
  - Varying time frame for each clinic
- Only includes genetic tests ordered by a genetic counselor
- Does not account for Direct to Consumer testing
- Only started collecting data on triple negative breast cancer in 2015
Biannual updates with Clinical Partners
   - Provide genetic clinics reports of their patient population regularly

Analyze data for Lynch Syndrome

Conduct workshops with Michigan Association of Health Plans (MAHP)
   - To provide resources and answer questions on testing, guidelines, policy, informed consent

Cascade Screening Call to Action Meeting on Sept. 29th

Increase Public Awareness
   - Ad campaign
   - Hereditary Colorectal Cancer Family Day on Nov 11th (Partnered with U of M)
MDHHS Clinical Network Participants

- Beaumont Cancer Genetics Program
- Beaumont Hospital-Dearborn Genetic Risk Assessment for Cancer Clinic
- Henry Ford Health System Cancer Genetics Program
- Karmanos Cancer Institute Cancer Genetic Counseling Service
- InformedDNA Telephone Genetic Counseling Services
- Mid-Michigan Hereditary Cancer Clinic
- Michigan State University Hereditary Cancer Program
- Marquette General Hematology/Oncology
- Munson Cancer Genetics Clinic
- Spectrum Health Cancer Genetics Program
- St. Joseph Mercy Hospital Cancer Genetics Program
- St. John Providence Health System Cancer Genetics Program (Southfield and Grosse Pointe Woods, MI)
- St. Mary Health Care Lacks Cancer Center Genetics (Grand Rapids, MI)
- St. Mary Mercy Our Lady of Hope Cancer Center (Livonia, MI)
- University of Michigan Breast and Ovarian Cancer Risk and Evaluation Program
- University of Michigan Cancer Genetics Clinic
- West Michigan Cancer Center

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References


Disclaimer

- Funding for this project was made possible in part by the Centers for Disease Control and Prevention. The views expressed herein do not necessarily reflect the official policies of the U.S. Department of Health and Human Services, nor does the mention of trade names, commercial practices, or organizations imply endorsement by the U.S. government.
THANK YOU!

Please contact Taylor Seaton at (517)373-2929/ seatont1@Michigan.gov for further questions or comments.