Incorporating Systematic Family History Collection into Public and Community Health Centers to Identify Women at High Risk for Hereditary Breast and Ovarian Cancer Syndrome (HBOC)

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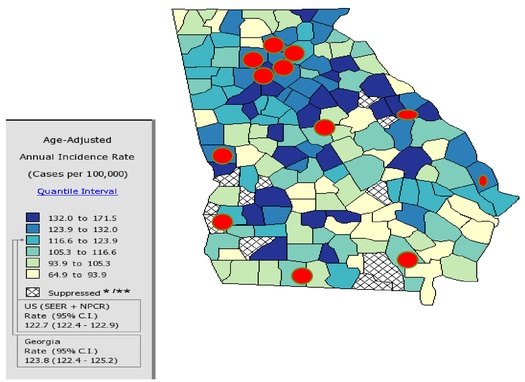
INTRODUCTION

Hereditary Breast and Ovarian Cancer (HBOC) accounts for 5-10% of all breast and ovarian cancer diagnoses. Limited knowledge of hereditary risk factors and family history are barriers to appropriate identification of women at risk for HBOC. To increase knowledge and appropriate genetic referrals, an educational module, screening, counselling and testing plan was developed for use in Georgia Public and Community Health Centers.

In collaboration with the Georgia Department of Public Health (DPH) and Emory University, the Georgia Center for Oncology Research and Education (CORE) increased the use of genomics education and risk assessment to reduce disparities among high risk minority women.

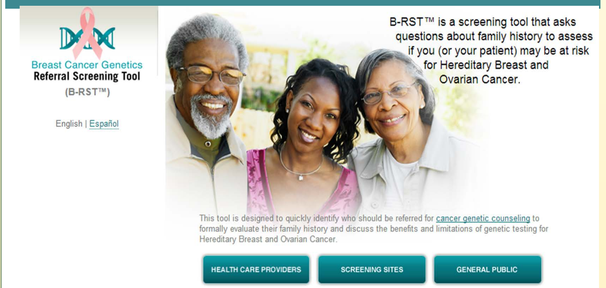
- Education of multi-disciplinary providers on evidence-based guidelines for Hereditary Breast and Ovarian Cancer (HBOC) and measurement of changes in knowledge and practice;
- Web-based risk assessment and education of pre-menopausal women (18 – 49) on HBOC with HIPAA- compliant data capture and data sharing capacity integrated into the web site;
- Coordination and management of referrals, genomic services and testing for women identified as high-risk for HBOC through implementation of a decision-management tracking tool to improve adherence to evidence-based guidelines.



HBOC BACKGROUND & DATA

Five to ten percent of all breast cancers are caused by gene mutations; the most common mutations can be found in the tumor suppressor breast cancer genes BRCA1/2. Individuals with a pathogenic mutation have HBOC, up to 65% lifetime risk of developing breast cancer, and a 39% lifetime risk of developing ovarian cancer. BRCA ½ mutation has a significant impact on incidence of and mortality in multiple cancers. The Georgia Department of Public Health estimates that with appropriate screening 750 to 2,353 potential BRCA-related breast and ovarian cancers could be prevented.

www.BreastCancerGeneScreen.org



- B-RST™ is a statistically validated screening tool developed by Cecelia Bellcross, PhD, MS, CGC of Emory University and recommended by the US Preventive Services Task Force (2013).
- B-RST™ uses six family history questions to engage and identify women who will benefit from genetic counseling.
- The tool takes less than five minutes to administer and provides instant screening results.
- In 2012, with funding from the CDC, the B-RST™ was successfully adapted to a web-based, tablet-enabled platform (now in English and Spanish) housed on BreastCancerGeneScreen.org.
- A HIPAA-compliant database for collection of demographic information and site-specific metrics is incorporated into the website and can be adapted for CCDR.
- These adaptations facilitate ease of use in a variety of clinical and community settings and allow for transferability to other settings.

GEORGIA BREAST CANCER GENOMICS PROJECT

The Breast Cancer Genomics Project is funded by the Georgia Department of Public Health in partnership with the Georgia Center for Oncology Research and Education. Over 5,000 women have been screened in 9 public health centers, 1 Federally Qualified Health Center and 1 safety net clinic in urban and rural communities. Three year data is presented below.

The project was designed to reach medically underserved women and successfully served a high percentage of racial and ethnic minorities (79%); there was a documented increase in knowledge of HBOC among primary care and public health professionals; web-basked risk assessment was implemented in public health clinics without additional staff; there was a high percentage of successful follow up (79%) among those who agreed to be contacted. Telephone access was utilized to facilitate provision of genomic services and a genetic testing fund was established to ensure all women had access to testing.

CLIENT OUTCOMES SUMMARY	2012-2015
Women 18 – 49 Screened Using B-RST™ through Public Health, Primary Care and Community Centers	5434
African American Women Screened Hispanic/Latino Women Screened	67% 12%
Screened positive on B-RST™	287 (5%)
Agreed to follow-up contact following positive screen	227
Completed detailed family history collection, pedigree development and provided resources, education, counseling	173
Referred for in-depth counseling and testing based in NCCN and other guidelines	40
Results of Genetic Testing • No mutation identified • Variant of uncertain significance identified • Pathogenic mutation identified in BRCA 2	 35 (88%) 4 (10%) 1 (2 %)
Diagnosed with breast cancer following positive B-RST™ screen and genetic risk assessment	9

CONCLUSIONS

- The introduction of genomics information within public health and community centers represents the opportunity for better access to cancer care through the provision of genetic counselling to uninsured individuals.
- Increased awareness of cancer genomics among pre-menopausal women, particularly racial/ethnic minorities and rural populations can lead to a reduction in barriers to genomic services and testing through the use of culturally-tailored information, navigation and consultation.
- Systematic family health history collection leads to guided discussion of resources with minimal additional workload for the providers.
- Oncology nurses are uniquely positioned to incorporate these principles in assessing and identifying their patients for candidates at high risk for a familial syndrome.
- The successful incorporation of systematic family history collection in the public and community health systems can serve as a model for integration of HBOC screening into additional venues.

REFERENCES

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GEORGIA core CENTER for ONCOLOGY RESEARCH & EDUCATION

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