

An observational study to assess service delivery in a sample of *BRCA* mutation carriers

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Background

- The identification of cancer predisposition genes (i.e. *BRCA1/2*) rapidly increased the need for experts in cancer genetics.
- Commercial marketing further increased consumer awareness of genetic testing.
- Healthcare professionals face increased pressure to provide genetic testing or refer to experts in genetic counseling.
- Genetic counseling and/or testing services are provided by a variety of healthcare professionals.
- The Commission on Cancer (CoC) and the National Accreditation Program for Breast Centers (NAPBC) standards have evolved to emphasize the importance of both pre- and post-test genetic counseling.

Objectives

- To explore:
- Who is providing genetic counseling and testing services for hereditary breast and ovarian cancer (HBOC)
 - Method of service provision
 - Knowledge about HBOC

To evaluate whether perceived service delivery methods meet CoC and NAPBC standards.

Methods

- BRCA* mutation carriers attending the 2011 Joining FORCEs Against Hereditary Cancer Conference completed a survey evaluating service delivery practices and knowledge of HBOC.
- The survey collected information on demographic, clinical, risk factor and service delivery aspects of care pertaining to those receiving testing for the *BRCA* genes.

ICARE Brochure

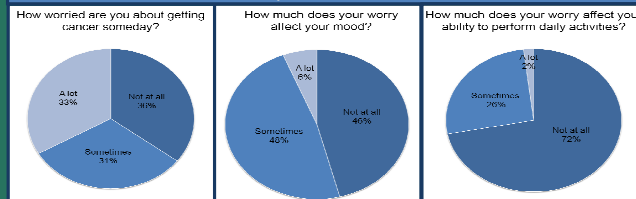


Summary of Key Findings

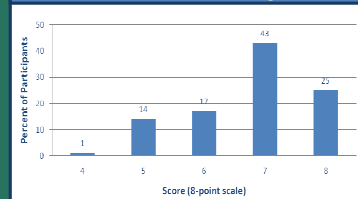
Pre-Test Provision of Cancer Genetics Services		Demographic and Clinical Variables		Knowledge of Hereditary Breast and Ovarian Cancer																			
Provider who ordered genetic testing Geneticist/Genetic Counselor 45 (40.9) Oncologist 25 (22.7) Obstetrician/Gynecologist 16 (14.5) Other (Surgeon/Internist) 13 (11.8) Family Doctor 11 (10.0)		Age (mean ± SD) 46.4 ± 11.6 Marital Status Married 75 (68.0) Other 35 (32.0)		<table border="1"> <thead> <tr> <th>Question</th> <th>% Correct</th> </tr> </thead> <tbody> <tr> <td>A father can pass down an altered inherited cancer gene to his children.</td> <td>100%</td> </tr> <tr> <td>An individual who does not have altered inherited cancer gene can still get cancer.</td> <td>99%</td> </tr> <tr> <td>An individual who has an altered inherited cancer gene has a higher risk for specific cancers.</td> <td>97%</td> </tr> <tr> <td>The sister of a woman with an altered inherited cancer gene has a 50% risk of having the altered gene.</td> <td>95%</td> </tr> <tr> <td>All individuals who have an altered inherited cancer gene get cancer.</td> <td>94%</td> </tr> <tr> <td>Early-onset cancers are more likely due to an altered inherited cancer gene than are late-onset cancers.</td> <td>75%</td> </tr> <tr> <td>One half of all cancer cases occur in individuals who have an altered inherited cancer gene.</td> <td>70%</td> </tr> <tr> <td>Approximately one in 10 individuals with cancer has an altered inherited cancer gene.</td> <td>47%</td> </tr> </tbody> </table>		Question	% Correct	A father can pass down an altered inherited cancer gene to his children.	100%	An individual who does not have altered inherited cancer gene can still get cancer.	99%	An individual who has an altered inherited cancer gene has a higher risk for specific cancers.	97%	The sister of a woman with an altered inherited cancer gene has a 50% risk of having the altered gene.	95%	All individuals who have an altered inherited cancer gene get cancer.	94%	Early-onset cancers are more likely due to an altered inherited cancer gene than are late-onset cancers.	75%	One half of all cancer cases occur in individuals who have an altered inherited cancer gene.	70%	Approximately one in 10 individuals with cancer has an altered inherited cancer gene.	47%
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Discussed risks and benefits of testing prior to blood draw Yes 95 (86.4) No 13 (11.8) Don't know 2 (1.8)		Race White 106 (96.4) Other 4 (3.6)																					
Provider who discussed information about genetic testing Geneticist/Genetic Counselor 79 (83.2) Other (Family Doc, Obs, Intern, Oncologist) 16 (18.8)		Education Level Less than High School 2 (1.9) Graduated High School 23 (21.3) Graduated College 38 (35.2) Postgraduate 45 (41.7)																					
Length of pre-test discussion ≤20 minutes 30 (31.9) ≥30 minutes 64 (68.1)		Household Income ≤\$49,999 20 (18.3) \$50,000-\$89,999 24 (22.0) ≥\$90,000 or more 55 (50.5) Prefer not to answer 10 (9.2)																					
Post-Test Provision of Cancer Genetics Services		Personal History of Cancer																					
Type of healthcare provider giving results Genetic Counselor 74 (67.3) Doctor 28 (25.5) Other (Nurse) 8 (4.5)		Breast 36 (32.7) Ovarian 8 (7.3) Other 7 (6.4) None 60 (54.5)																					
Method of Notification about Test Results In person appointment 68 (61.8) By phone 40 (36.4) Other 2 (1.8)		Prophylactic Mastectomy Yes 45 (59.1) No 65 (40.9)																					
Length of post-test discussion ≤20 minutes 67 (62.6) ≥30 minutes 40 (37.4)		Prophylactic Oophorectomy Yes 71 (64.5) No 39 (35.5)																					
Patient referrals* Surgeon 53 (39.3) Clinical Oncologist 42 (30.4) Other 22 (15.9) Genetic Counselor/ Clinical Geneticist 21 (15.2)		Mutation Status <i>BRCA1</i> Positive 65 (59.1) <i>BRCA2</i> Positive 45 (40.9)																					

*Participants could select more than 1 answer

Psychosocial Variables



Distribution of Total HBOC Knowledge Scores



CoC and NAPBC Standards

- Commission on Cancer (CoC) **Standard 2.3 Risk: Assessment and Genetic Counseling:** Cancer risk assessment, genetic counseling, and testing services are provided to patients either on-site or by referral, by a qualified genetics professional.
- National Accreditation Program for Breast Centers (NAPBC) **Standard 2.16: Genetic Evaluation and Management:** Genetic risk assessment, genetic counseling, and genetic testing services are provided or referred.

Conclusions

- Although the majority of *BRCA* mutation carriers reported that a geneticist/genetic counselor was involved in the genetic counseling process, our results clearly demonstrate involvement of numerous practitioners from a variety of medical specialties.
- It appears that many of our participants met the standards set by the CoC and NAPBC requiring pre- and post-test counseling by a genetics professional. This study, however, cannot definitively determine whether the pre- and post-test counseling met the CoC/NAPBC minimum defined requirements and will be assessed through future efforts.
- BRCA* mutation carriers involved with advocacy organizations (i.e. FORCE) may have enhanced knowledge about HBOC.

Future Directions

- Although *BRCA* mutation carriers in the study self-reported that a genetic counselor/geneticist was involved in their genetic counseling and testing, we plan to confirm that a trained genetics professional was involved.
- Determine if cancer genetics service delivery and knowledge of HBOC differs among *BRCA* mutation carriers recruited at FORCE and elsewhere.
- Determine if the time elapsed between genetic testing and attendance at FORCE affects knowledge.

Acknowledgements

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