Oregon Health Authority – Public Health Division

Oregon's Approach to Increasing Awareness of Hereditary Breast and Ovarian Cancer Syndrome (HBOC) among Clinicians and Patients

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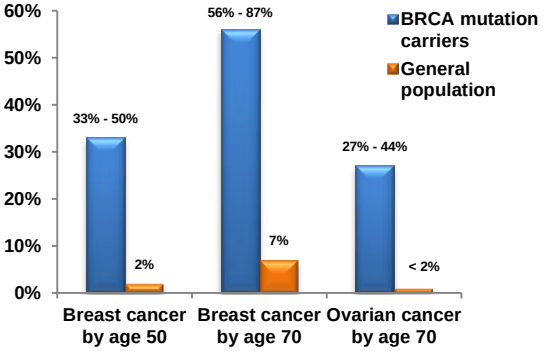
Background: Hereditary Breast and Ovarian Cancer Syndrome (HBOC) accounts for 5 to 10% of all breast cancers and about 15% of ovarian cancers.[1] A majority of HBOC cancers are due to mutations in the BRCA1 and BRCA2 genes.

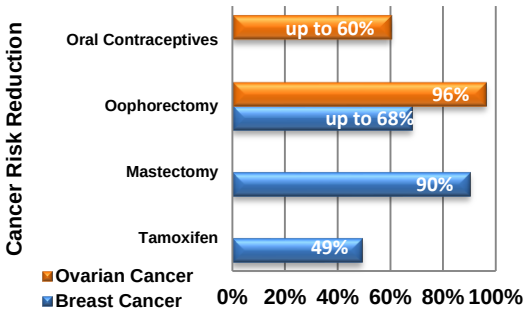
Physician and patient education leading to greater use of genetic services can result in early detection of tumors or risk reduction through prophylactic measures.

Risks of Cancer among Women with BRCA+ Gene Mutations



Data Source: InheritedRisk.Com. Taking Action to Prevent Cancer. [Cited 2012 May 22]; Available from: http://www.inheritedrisk.com/taking-action/

Proportion of Cancer Risk Reduction through Preventive Measures among Women with BRCA+ Gene Mutations



Data Source: InheritedRisk.Com. Taking Action to Prevent Cancer. [Cited 2012 May 22]; Available from: http://www.inheritedrisk.com/taking-action/

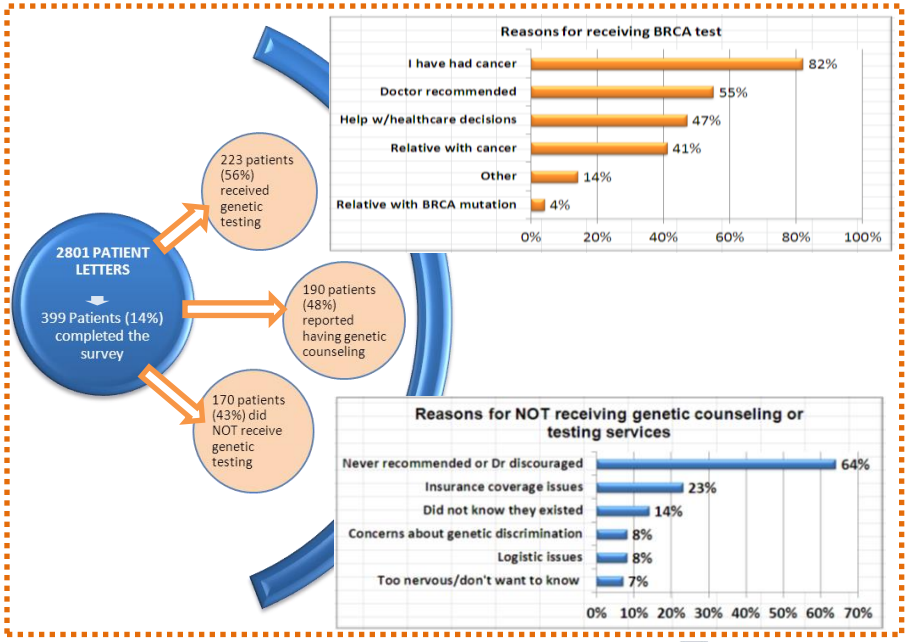
Methods: In collaboration with the Oregon Genetics Program (OGP), the Oregon State Cancer Registry (OSCaR) identified 2,801 patients diagnosed with cancers from 2009 to 2011 that met at least one of the following National Comprehensive Cancer Network (NCCN) criterion for referral to genetic risk evaluation[2]

NCCN guidelines for referral to genetic services:

- Breast cancer at ≤ 50 years
- Triple negative (ER-, PR-, HER2-) Breast cancer
- Ovarian cancer
- Males with Breast cancer

Educational letters containing information about risks associated with HBOC, benefits of genetic counseling and contact information for local genetic services were mailed to these selected clinicians and patients. All patients and clinicians received a link to an online survey to assess their familiarity with and possible use of genetic testing and counseling. The patient survey was 15 minutes long and the provider survey took only a minute. A $2 bill was included with the patient letter as an incentive for completing the survey.

Results: A total of 399 (14%) of patients and 5 (<1%) of physicians completed the survey. Among respondents, 47.6% had received genetic counseling and 55.9% had received the BRCA genetic test. The most common reason for NOT receiving genetic counseling or testing was that they were never recommended (56.5%) and the next frequent reason was insurance coverage issues (22.9%). Respondents who had not received counseling or genetic testing were more likely to have learned new information (57.1%) from the letters or thought the information was useful, and were more likely to be prompted to take action.



Patient's positive responses to the letters

	Learned new information			Believe information was useful			Prompted or will prompt action		
	Percent[1]	Odds Ratio	(95% CI)	Percent[1]	Odds Ratio	(95% CI)	Percent[1]	Odds Ratio	(95% CI)
Total	42.3			54.5			26.9		
Received Counseling									
Yes	24.9	1.000 [2]		45.1	1.000 [2]		13.1	1.000 [2]	
No	57.1	4.017 *	(2.58-6.25)	63.4	2.103 *	(1.39-3.19)	40.0	4.417 *	(2.63-7.43)
Received Testing									
Yes	27.2	1.000 [2]		46.1	1.000 [2]		12.0	1.000 [2]	
No	61.6	4.294 *	(2.75-6.71)	64.9	2.163 *	(1.41-3.3)	47.0	6.475 *	(3.84-10.93)

[1] Percent in each category that responded "Strongly Agree" or "Agree" to the question. Denominator excludes missing responses.

[2] Logistic regression reference category. *p≤.05

Conclusions: Central cancer registries can be used to promote awareness and discussions of HBOC among patients and providers, and thus increase referrals to genetic services.

References:

[1] National Cancer Institute Fact Sheet BRCA1 and BRCA2: Cancer Risk and Genetic Testing. Accessed 12/05/2013 at http://www.cancer.gov/cancertopics/factsheet/Rick/BRCA

[2] National Comprehensive Cancer Network, Clinical Practice Guidelines in Oncology. Genetic/Familial High-Risk Assessment: Breast and Ovarian. Version 4.2013.

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