

Knowledge and Awareness of Genetic Testing for Breast & Ovarian Cancer in Connecticut

Joan Foland, MHS, MPhil

Background

Breast and ovarian cancers are a major public health issue in Connecticut. Breast and ovarian cancer are the second and fifth leading causes of cancer-related death among women in Connecticut.¹ In addition, Connecticut ranks as one of the highest states in the nation for breast cancer incidence rates and in the top 15 for ovarian cancer.² Though breast cancer is most commonly thought of as a woman's disease, male breast cancer also occurs.

Most women in Connecticut appear to be aware of the link between genetics and breast cancer. Based on a 2005 survey of Connecticut women, 95% felt that "having the breast cancer gene" was a *very* (84%) or *somewhat* (11%) important factor in increasing the risk of a woman getting breast cancer.³

Genetic testing for hereditary breast and ovarian cancer (HBOC) has been available since 1996 from the biotechnology company Myriad Genetics. Direct-to-consumer marketing of genetic tests is a more recent phenomenon. From September 2002 to February 2003, Myriad Genetics piloted a media campaign in Atlanta and Denver to raise awareness about the availability of genetic testing for breast and ovarian cancer susceptibility. Between September 2007 and Spring 2008, Myriad Genetics launched another advertising campaign in the Northeast, specifically in Hartford, New York City, Boston, and Providence.

Although Connecticut's residents are highly educated⁴ and appear to be aware of a link between genetics and breast cancer, it is unknown whether this translates into knowledge about genetic testing for breast cancer and whether a regional advertising effort heightened awareness in the state. To address this issue, the Connecticut Department of Public Health (DPH) Genomics Office utilized a statewide survey to assess the knowledge of men and women in Connecticut about genetic testing for hereditary breast and ovarian cancer and to determine the factors influencing their knowledge, the results of which can be used to refine future educational programs.

Methods

Data from the 2008 Connecticut Behavioral Risk Factor Surveillance System (BRFSS) survey were used to evaluate Connecticut residents' knowledge and awareness about genetic testing for breast and ovarian cancer. The BRFSS, a joint effort between the Centers for Disease Control and Prevention (CDC) and the Connecticut Department of Public Health, collects data about demographic status, health status, health risk behaviors, and healthcare access and utilization using a random-digit dialed telephone cross-sectional methodology. A disproportionate stratified random sampling method is used to ensure that a representative sample is collected from the non-institutionalized Connecticut population 18 years of age and older. Sample data are weighted to reflect the demographic characteristics of the adult population in Connecticut.

To measure the self-reported assessment of genetic-testing knowledge, Connecticut adults were asked: *How would you describe your overall knowledge about genetic testing for breast and ovarian cancer?* Respondents answered *none, little, some, or a lot*. To measure awareness of the advertising campaign by Myriad Genetics, adults were asked: *Have you seen or heard an advertisement about a genetic test to determine a woman's risk for breast or ovarian cancer in the past 6 months?*

Data were analyzed using SAS software Release 9.2, taking into account the complex sampling design of the BRFSS to produce results based on the weighted data. Statistical procedures included frequency distributions, chi-square testing of hypotheses, and predictive modeling with multinomial logistic regression. Stratification by sex allowed for differentiation between men and women of characteristics associated with knowledge of genetic testing. Only variables that were significantly associated with knowledge of genetic testing for HBOC were left in the final logistic regression models. Some of the values of the independent variables were collapsed if no significant differences were found between them.

Table 1. Selected characteristics by knowledge and awareness of genetic testing for breast and ovarian cancer among female respondents in Connecticut, 2008 Behavioral Risk Factor Surveillance System

Characteristic	Respondents ^a	Knowledge of Genetic Testing for HBOC			Saw/Heard Ad n (weighted %)
		None/Little n (weighted %)	Some n (weighted %)	A lot n (weighted %)	
Total Female	3,562	1,544	1,255	763	1,895
Age					
18-44	986	500 (51.6%)	333 (33.7%)	153 (14.8%)	462 (47.8%)
45-64	1,376	553 (41.7%)	488 (35.0%)	335 (23.4%)	771 (57.8%)
65+	1,143	471 (41.4%)	407 (34.7%)	265 (23.9%)	628 (55.6%)
Education					
High school or less	1,196	608 (54.5%)	379 (32.0%)	209 (13.5%)	653 (54.8%)
Some college	854	377 (47.9%)	308 (33.9%)	169 (18.3%)	462 (53.9%)
College graduate	1,504	557 (39.1%)	563 (36.3%)	384 (24.6%)	776 (51.1%)
Household income					
Less than \$25,000	686	343 (54.8%)	207 (27.3%)	136 (18.0%)	369 (55.3%)
\$25,000 – 49,999	693	310 (48.9%)	255 (35.6%)	128 (15.5%)	365 (50.6%)
\$50,000 – 74,999	480	219 (53.8%)	162 (31.5%)	99 (14.8%)	266 (52.3%)
\$75,000+	1,136	419 (37.8%)	427 (37.1%)	290 (25.1%)	599 (54.2%)
Race/Ethnicity ^b					
White/nH	2,849	1,207 (45.0%)	1,023 (34.8%)	619 (20.2%)	1,515 (52.9%)
Black/nH	236	107 (48.8%)	79 (33.2%)	50 (18.0%)	134 (60.3%)
Other race/nH	128	68 (54.1%)	35 (26.3%)	25 (19.7%)	64 (49.7%)
Hispanic	296	141 (49.8%)	98 (35.2%)	57 (15.0%)	150 (49.8%)
Marital Status					
Ever married	2,934	1,240 (44.5%)	1,047 (35.1%)	647 (20.4%)	1,582 (53.4%)
Never married	598	293 (52.2%)	197 (32.1%)	108 (15.7%)	296 (51.1%)

^a The number of respondents may not total across characteristics because of missing data.

^b nH = nonHispanic

Table 2. Selected characteristics by knowledge and awareness of genetic testing for breast and ovarian cancer among male respondents in Connecticut, 2008 Behavioral Risk Factor Surveillance System

Characteristic	Respondents ^a	Knowledge of Genetic Testing for HBOC			Saw/Heard Ad n (weighted %)
		None/Little n (weighted %)	Some n (weighted %)	A lot n (weighted %)	
Total Male	2,184	1,428	523	233	969
Age					
18-44	588	413 (67.3%)	127 (24.2%)	48 (8.5%)	242 (44.8%)
45-64	905	560 (60.5%)	241 (28.6%)	104 (11.0%)	415 (44.9%)
65+	672	446 (66.3%)	149 (22.1%)	77 (11.6%)	304 (46.2%)
Education					
High school or less	642	489 (75.1%)	97 (17.5%)	56 (7.4%)	303 (48.9%)
Some college	430	296 (67.3%)	107 (25.8%)	27 (6.9%)	188 (46.0%)
College graduate	1,106	637 (57.0%)	319 (30.5%)	150 (12.6%)	475 (42.1%)
Household income					
Less than \$25,000	280	218 (82.5%)	45 (12.0%)	17 (5.5%)	114 (39.0%)
\$25,000 – 49,999	405	290 (64.8%)	84 (29.7%)	31 (5.5%)	192 (50.6%)
\$50,000 – 74,999	307	202 (65.2%)	71 (21.2%)	34 (13.8%)	134 (43.3%)
\$75,000+	959	558 (60.0%)	268 (27.9%)	133 (12.1%)	428 (43.9%)
Race/Ethnicity ^b					
White/nH	1,798	1,145 (62.9%)	456 (26.7%)	197 (10.4%)	794 (45.6%)
Black/nH	102	79 (83.5%)	19 (13.7%)	4 (2.8%)	58 (53.2%)
Other race/nH	94	67 (67.8%)	19 (27.1%)	8 (5.1%)	30 (26.0%)
Hispanic	133	100 (73.0%)	15 (16.5%)	18 (10.4%)	59 (45.1%)
Marital Status					
Ever married	1,767	1,122 (62.3%)	442 (25.8%)	203 (11.9%)	802 (45.2%)
Never married	400	298 (71.0%)	75 (24.6%)	27 (4.4%)	158 (43.9%)

^a The number of respondents may not total across characteristics because of missing data.

^b nH = nonHispanic

Results

There were 5,746 respondents who answered the BRFSS questions about genetic testing for HBOC, of which 3,562 were female and 2,184 were male. Tables 1 and 2 present the background characteristics of the female and male respondents, respectively. Sample sizes (number of survey respondents) are reported as unweighted numbers.

Table 3. Knowledge and awareness of genetic testing for breast and ovarian cancer among respondents in Connecticut, 2008 Behavioral Risk Factor Surveillance System

Question	Male Respondents			Female Respondents		
	Number	Weighted %	95% CI	Number	Weighted %	95% CI
How would you describe your overall knowledge about genetic testing for breast and ovarian cancer?						
Little/None	1,428	64.5%	61.5%-67.6%	1,544	46.0%	43.6%-48.3%
Some	523	25.6%	22.7%-28.5%	1,255	34.4%	32.2%-36.6%
A lot	233	9.9%	8.2%-11.6%	763	19.6%	17.9%-21.4%
Saw/heard an advertisement about a genetic test to determine a woman's risk for breast or ovarian cancer in the past 6 months	969	45.0%	41.9%-48.2%	1,895	52.8%	50.5%-55.2%

Table 4. Likelihood of 'Some' or 'A lot' of reported knowledge about genetic testing for breast and ovarian cancer among male and female respondents in Connecticut, 2008 Behavioral Risk Factor Surveillance System

Independent variable	Males' Knowledge of Genetic Testing		Females' Knowledge of Genetic Testing	
	Some (vs. Little/None) Adjusted OR ^a (95% CI)	A lot (vs. Little/None) Adjusted OR ^a (95% CI)	Some (vs. Little/None) Adjusted OR ^a (95% CI)	A lot (vs. Little/None) Adjusted OR ^a (95% CI)
Age				
18-44			ref	ref
45-64	*	*	1.2 (0.9 – 1.6)	1.8 (1.3 – 2.4) ^d
65+			1.5 (1.1 – 2.0) ^d	2.7 (1.9 – 3.9) ^d
Education				
High school or less	ref	ref	ref	ref
Some college	ref	ref	1.1 (0.8 – 1.5)	1.5 (1.0 – 2.3) ^d
College graduate	2.2 (1.5 – 3.2) ^{b,d}	2.1 (1.4 – 3.3) ^{b,d}	1.3 (1.0 – 1.8)	2.2 (1.6 – 3.1) ^d
Household income				
Less than \$50,000	ref	ref	ref	ref
\$50,000 – 74,999	0.9 (0.5 – 1.5)	2.6 (1.2 – 5.4) ^d	ref	ref
\$75,000+	1.1 (0.7 – 1.7)	2.1 (1.2 – 3.5) ^d	1.6 (1.2 – 2.1) ^{c,d}	1.9 (1.4 – 2.6) ^{c,d}
Saw/heard an ad				
No	ref	ref	ref	ref
Yes	2.6 (1.8 – 3.7) ^d	4.6 (2.9 – 7.2) ^d	1.9 (1.5 – 2.4) ^d	3.1 (2.4 – 4.2) ^d

OR = odds ratio; CI = confidence interval; ref = reference group

* AGE was not significantly associated with males' knowledge

^a Odds ratios are adjusted for all other independent variables in the model

^b College graduate vs. Not a college graduate

^c Household income \$75,000 or more vs. Less than \$75,000

^d p < 0.05

Women tended to indicate a greater knowledge of genetic testing for HBOC than men. Female respondents were twice as likely to describe their knowledge as 'a lot' (19.6%) compared to male respondents (9.9%) and 1.3 times as likely to describe their knowledge as 'some' (34.4%) compared to males (25.6%) (Table 3). Female respondents were also more likely than male respondents to have seen or heard about an ad for genetic testing for HBOC (52.8% vs. 45.0%).

Multivariate assessments of the association between demographic factors and knowledge of genetic testing were performed independently for males and females. For female respondents, older age, high educational level, high income, and 'having seen an ad about genetic testing' correlated positively with knowledge about genetic testing for HBOC. Race/ethnicity and marital status did not show a significant association when other covariates were taken into account. Only age was associated with awareness of the availability of genetic testing, with approximately 57% of middle-aged or older female respondents having seen an ad versus 48% of females aged 18 to 44.

Logistic regression analyses showed that female respondents who were 65 years or older were 2.7 times more likely to report knowing 'a lot' about genetic testing for HBOC versus female respondents 18-44 years of age (Table 4). Female respondents with a college degree were 2.2 times more likely to report knowing 'a lot' compared to female respondents with a high school degree or less. Female respondents with a household income of \$75,000 or more had a 1.9 times greater odds of indicating they know 'a lot' compared to female respondents with household

incomes less than \$75,000. Female respondents who indicated that they had seen or heard an advertisement for genetic testing for HBOC were 3.1 times more likely to report that they know ‘a lot’ about genetic testing than female respondents who had not seen an ad.

For male respondents, educational attainment, income, and ‘having seen an ad about genetic testing’ showed a significant association with knowledge about genetic testing for HBOC, whereas age, race/ethnicity, and marital status did not after adjusting for other covariates.

Male respondents with a college degree were 2.1 times more likely to report knowing ‘a lot’ compared to male respondents with less than a college degree (Table 4). Male respondents with a household income of \$75,000 or more were 2.1 times more likely to describe their knowledge of genetic testing as ‘a lot’ compared to male respondents with household incomes less than \$50,000, and males with a household income of \$50,000 to \$74,999 had a 2.6 times greater odds of indicating they know ‘a lot’ compared to males with household incomes less than \$50,000.

Compared with those who reported knowing little or none about genetic testing, male respondents who indicated that they had seen or heard an advertisement for genetic testing for HBOC were 2.6 times more likely to report that they know ‘some,’ and 4.6 times more likely to report knowing ‘a lot,’ about genetic testing than male respondents who had not seen an ad.

Discussion

Sixty-five percent of male respondents in Connecticut indicated that they know ‘little or none’ about genetic testing for HBOC. Because male hereditary breast cancer is rare, genetic testing may not seem to have personal health importance for men. A recent study, however, suggests that the risks of breast cancer are sufficient enough to warrant awareness of breast cancer among men in BRCA2 families.⁵ There may also be familial implications for their mothers, wives, or daughters, of which they should be aware. Educational efforts about genetic testing for HBOC should also be targeted toward younger, less educated and less affluent females in Connecticut, the majority of whom reported knowing ‘little or none’ about genetic testing for HBOC.

Results for Connecticut show that ‘having seen or heard about an ad about genetic testing for HBOC’ appears to be associated with both men’s and women’s self-reported knowledge of genetic testing even after controlling for other factors, such as age, educational attainment, and household income. These results vary from those found in a previous study. Following the 2003 public awareness campaign by Myriad Genetics, the Centers for Disease Control and Prevention and several state health departments surveyed female consumers from pilot cities that had been targeted by Myriad’s campaign (Atlanta and Denver) and control cities that had not been targeted (Raleigh-Durham and Seattle) to assess the campaign’s impact. Although women in the pilot cities were more likely than those in the two comparison cities to have seen or heard an advertisement, perceived knowledge about testing did not differ between women in the pilot and comparison cities.⁶ The reasons for these differences are unknown, although genetic testing in general has received increasing attention since the completion of the Human Genome Project in the spring of 2003.

The BRFSS survey only assessed “self-reported” knowledge of genetic testing for HBOC, which may not necessarily be accurate. For instance, when Connecticut women were asked about a woman’s risk of developing breast cancer in her lifetime, respondents stated that 40% of women were at risk for the disease, which is far greater than the 12.5% risk the average American woman faces.³ From a public health perspective, a potential benefit of a population-based marketing campaign is increased awareness and knowledge among consumers in Connecticut about genetic testing. Conversely such ads may exaggerate benefits in order to sell tests, and may not adequately reflect the limitations of testing. Therefore, people may not truly understand that genetic testing for HBOC is recommended only for a small percentage of women in the general population, that genetic testing has many limitations, and that professional counseling should accommodate genetic testing.

The DPH Genomics Office will use these findings in its ongoing efforts to educate consumers about genetic testing for breast and ovarian cancer as well as other chronic diseases for which commercial companies market genetic tests directly to consumers.

References

- 1 Connecticut Department of Public Health 2005-2007 Age-adjusted Mortality Rates. Available at: www.ct.gov/dph/lib/dph/hisr/hcqsar/mortality/xls/aamr_state_3yr_aggregate.xls.
- 2 U.S. Cancer Statistics Working Group. United States Cancer Statistics: 1999–2006 *Incidence and Mortality Web-based Report*. Atlanta: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention and National Cancer Institute; 2010. Available at: www.cdc.gov/uscs.
- 3 Environment and Human Health, Inc. 2006. *Breast Cancer: What Science Knows, What Women Think*. Environment and Human Health, Inc., North Haven, CT.
- 4 U.S. Census Bureau, Statistical Abstract of the United States: 2010 (129th Edition) Washington, DC, 2009. Accessed www.census.gov/compendia/statab on June 29, 2010.
- 5 Evans DG, Susnerwala I, Dawson J, et al. Risk of breast cancer in male BRCA2 carriers. *J Med Genet*. Published Online First: 28 June 2010. doi:10.1136/jmg.2009.075176.
- 6 CDC. Genetic testing for breast and ovarian cancer susceptibility: evaluating direct-to-consumer marketing – Atlanta, Denver, Raleigh-Durham, and Seattle, 2003. *MMWR* 2004; 53: 603-606.

