J Genet Counsel (2017) 26:859–865
DOI 10.1007/s10897-016-0064-5

ORIGINAL RESEARCH

Large, Prospective Analysis of the Reasons Patients Do Not Pursue *BRCA* Genetic Testing Following Genetic Counseling

Sommer Hayden[1] · Sarah Mange[2] · Debra Duquette[2] · Nancie Petrucelli[3] · Victoria M. Raymond[4] · on behalf of the BRCA Clinical Network Partners

Received: 11 January 2016 / Accepted: 29 December 2016 / Published online: 16 January 2017

Abstract Genetic counseling (GC) and genetic testing (GT) identifies high-risk individuals who benefit from enhanced medical management. Not all individuals undergo GT following GC and understanding the reasons why can impact clinical efficiency, reduce GT costs through appropriate identification of high-risk individuals, and demonstrate the value of pre-GT GC. A collaborative project sponsored by the Michigan Department of Health and Human Services prospectively collects anonymous data on *BRCA*-related GC visits performed by providers in Michigan, including demographics, patient/family cancer history, GT results, and reasons for declining GT. From 2008 to 2012, 10,726 patients underwent GC; 3476 (32.4%) did not pursue GT. Primary reasons included: not the best test candidate (28.1%), not clinically indicated (23.3%), and insurance/out of pocket cost concerns (13.6%). Patient disinterest was the primary reason for declining in 17.1%. Insurance/out of pocket cost concerns were the primary reason for not testing in 13.4% of untested individuals with private insurance. Among untested individuals with breast and/or ovarian cancer, 22.5% reported insurance/out of pocket cost concerns as the primary reason for not testing and 6.6% failed to meet Medicare criteria. In a five-year time period, nearly one-third of patients who underwent *BRCA* GC did not pursue GT. GT was not indicated in almost half of patients. Insurance/out of pocket cost concerns continue to be barriers.

Keywords Genetic Counseling · Genetic Testing · Barriers · BRCA · Insurance · Public Health

✉ Victoria M. Raymond
vmraymond@gmail.com

[1] Saint Joseph Mercy Hospital, Ann Arbor, MI, USA

[2] Michigan Department of Health and Human Services, Lansing, MI, USA

[3] Barbara Ann Karmanos Cancer Institute, Detroit, MI, USA

[4] University of Michigan Health System, 300 North Ingalls, NI3 A08, Ann Arbor, MI 48109-5419, USA

Introduction

Hereditary Breast and Ovarian Cancer due to germline mutations in the tumor suppressor genes, *BRCA1* (OMIM#113705) and *BRCA2* (OMIM#600185) is the most common inherited breast and ovarian cancer condition and accounts for approximately 7% of all breast cancer diagnoses (Claus et al. 1996; Pal et al. 2005). Women with germline *BRCA* mutations have an estimated 40–80% lifetime risk of breast cancer and an estimated 11–44% risk of ovarian cancer (Chen and Parmigiani 2007; Chen et al. 2006; King et al. 2003). The risk of other cancers, including male breast cancer, pancreatic cancer, melanoma, and prostate cancer, are also elevated in individuals with germline *BRCA* mutations. Risk-reduction strategies have proven beneficial in improving clinical outcomes, thus demonstrating the importance of identifying high-risk individuals (Domchek et al. 2006; Hartmann et al. 1999, 2001; Rebbeck et al. 2009; Saslow et al. 2007).

In the era of precision medicine, genetic counseling (GC) and genetic testing (GT) can identify individuals with elevated cancer risk for enrollment into these enhanced cancer surveillance programs. Personal history of breast cancer, Ashkenazi Jewish descent, strength of the family cancer history, heighted personal risk perception, and desire for cancer risk information are positively associated with patient uptake of GT (Armstrong et al. 2000; Ropka et al. 2006). Although awareness of the availability of *BRCA* GT continues to increase,

women who are referred to GC may not proceed with GT for a variety of reasons (Borzekowski et al. 2014; Mai et al. 2014). Previous studies have shown that affordability and insurance, family concerns, fear of adverse psychological consequences, logistic problems, and concerns regarding discrimination may influence GT decisions (Armstrong et al. 2000; Godard et al. 2007; Kieran et al. 2007; Thompson et al. 2002). Factors associated with GT uptake may also differ based on gender and other demographic characteristics, such as education level (Godard et al. 2007; Goelen et al. 1999; Hallowell et al. 2005; Olaya et al. 2009; Thompson et al. 2002). Increasing demands for GC, expanding insurance coverage for GT, federal and state legislature to protect against GT discrimination, and increasing awareness among patients and providers about the benefits of GT has further evolved the field of clinical genomics. In this new era, our current understanding of the reasons individuals decline GT following GC is incomplete. Expanding our understanding of the clinical, demographic, and psychosocial factors impacting GT decision making is a necessary component to the integration of GT into clinical management, allowing for the ability to address potential barriers, and identification of how GC professionals can adjust to meet current demands. The current study uses a unique clinical state database to collect and analyze the reasons individuals did not pursue *BRCA1* and *BRCA2* GT following GC and risk assessment.

Materials and Methods

Data and Reporting

The Michigan Department of Health and Human Services (MDHHS) developed a statewide surveillance network including fifteen clinical facilities providing cancer GC to Michigan patients by board-certified/board-eligible cancer genetics providers. These facilities are located within the state, with the exception of one out of state organization providing GC services to Michigan patients by telephone. Participating facilities prospectively report data for all patients receiving *BRCA* GC, including demographics, patient and family cancer history, and information derived during the GC and GT process, including reasons for declining *BRCA* testing. These data do not include patient names or identifiers.

Individuals seen for *BRCA* GC between January 1, 2008 and December 31, 2012 at a participating clinical facility were included in the analysis. The status of undergoing a *BRCA* test was defined as having any type of test (single site, Ashkenazi founder mutation analysis, full sequencing and/or rearrangement testing) at any time prior to, or after GC. *BRCA* GT status was continuously updated in the database for a minimum of nine months past the date of counseling, so that the tests of patients who may have delayed testing for several months were recorded.

Family cancer history was defined by the study team according to the 2005 United States Preventive Services Task Force (USPSTF) recommendation for GC referral ("Genetic risk assessment and BRCA mutation testing for breast and ovarian cancer susceptibility: recommendation statement." 2005), the latest available USPSTF recommendation at the time GC took place. High risk individuals were those who met at least one of the following criteria: two first-degree relatives with breast cancer, at least one of whom had breast cancer at or before age 50; three or more first-or second-degree relatives with breast cancer; a combination of both breast and ovarian cancer among first- and second-degree relatives; a first-degree relative with bilateral breast cancer; two or more first- or second-degree relatives with ovarian cancer; a first- or second-degree relative with both breast and ovarian cancer; breast cancer in a male relative; Ashkenazi Jewish ancestry and at least one first-degree relative with breast or ovarian cancer; or Ashkenazi Jewish ancestry with at least two-second degree relatives on the same side of the family with breast and/or ovarian cancer. Personal and family cancer histories and age of diagnoses were based on self-report at the time of counseling, with possible verification through health system records. The definition of breast cancer included ductal carcinoma in situ.

Reasons for Not Testing

As part of the standard reporting process, at each visit the genetics provider assigned the patient a single reason for not testing according to a pre-determined menu of common reasons. The menu options were designed through the expert opinion of the genetic providers from the participating clinical facilities (Table 2). For patients who did not test and were seen for GC multiple times, the most recent reason for not testing was used for analysis. Reasons for not testing were also grouped by medically indicated reasons (testing was not clinically indicated or that the patient was not the best test candidate in the family) and non-medically indicated reasons (insurance/out of pocket cost concerns, discuss options with relatives, does not meet Medicare criteria, patient disinterest, reassured by risk assessment, arrange life or disability insurance, and "other") (Fig. 1, Table 3). "Not a good time", "does not want to know", and "patient sees no benefit" indicated patient decision not to test, thus these responses were combined into the single "patient disinterest" variable.

Some reasons were mutually exclusive. For instance, the insurance/out of pocket cost concerns category includes both uninsured and those who self-defined as having deductibles, co-insurance, or co-pays that impeded testing. If a patient failed to meet insurance criteria because of low risk, and the provider did not believe GT was indicated, the reason for not

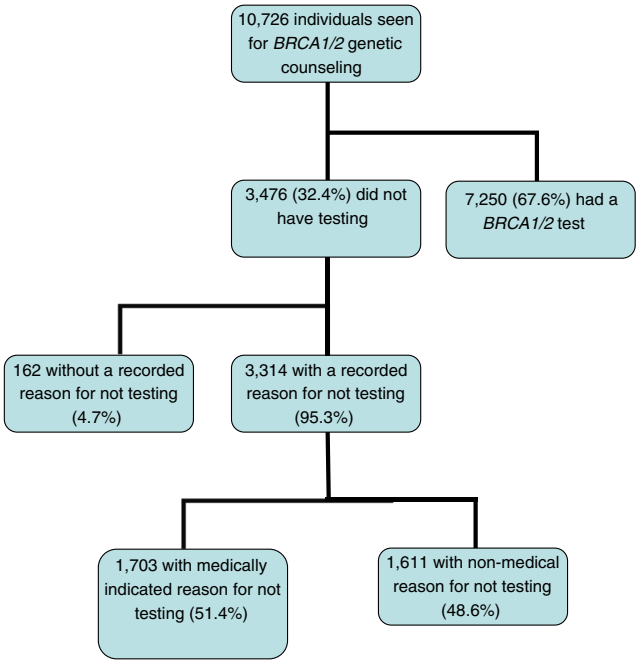

Fig. 1 Reasons for not testing among individuals seen for BRCA1/2 genetic counseling from January 1, 2008 to December 31, 2012

testing was considered to be that GT was not clinically indicated rather than insurance/out of pocket cost concerns or not meeting Medicare criteria. Similarly, the determination that GT was not clinically indicated was made by the provider, whereas the status of being reassured by the risk assessment refers to the patient's determination of clinical need.

Analysis

Frequencies and percentages were calculated to describe GT patterns, reasons for not testing, and the demographic characteristics of those with specific reasons for not testing. Characteristics of those who had or did not have GT were compared with chi-square tests. Post-hoc chi square testing was conducted to examine test patterns among black versus white patients and those with a personal history of breast and/or ovarian cancer versus no personal history of cancer. Insurance/out of pocket cost concerns as a barrier to GT was examined by year from 2008 to 2012 with Cochran-Armitage trend tests. All analyses were conducted using the SAS 9.3 statistical package.

These data are consistent with public health surveillance and not research as defined by the code of federal regulations (CFR) 46.102 (D) and therefore were deemed exempt by the Michigan Department of Health and Human Services (MDHHS) Institutional Review Board (IRB) for the Protection of Human Research Subjects. The collaborative project was reviewed by the IRB's of each individual institution.

Results

There were 10,726 patients who received *BRCA*-related GC by a board-certified/eligible genetic counselor or geneticist in the state of Michigan between 2008 and 2012. The majority of patients presenting for GC were female (N = 10,164; 94.8%) and white (N = 8830; 82.3%); over half (N = 6000; 56.0%) had a personal history of breast and/or ovarian cancer (Table 1).

Approximately one-third (32.4%) of individuals did not have *BRCA* GT after GC (Fig. 1, Table 1). In a comparison of black versus white patients, black patients presenting for GC were significantly less likely to have GT following GC than white patients. 42.5% (N = 345) of black patients were not tested as compared to 31.0% (N = 2740) of white patients ($p < 0.01$).

Nearly one-third of those who did not have GT had a personal history of breast and/or ovarian cancer; however, patients with cancer (breast and/or ovarian) were more likely to have GT than those without a personal history of cancer ($p < 0.01$). While 51.8% (N = 2450) of patients without a personal history of breast or ovarian cancer had *BRCA* testing, 79.5% (N = 4390) of those with breast cancer, 84.4% (N = 314) of those with ovarian cancer, and 88.9% (N = 96) of those with both breast and ovarian cancer had GT (Table 1). Individuals presenting for GC with a known mutation in the family comprised 12.2% (N = 6066) of patients counseled, and 90.4% of these patients had testing compared to 64.4% of those without a known family mutation (Table 1).

Reasons for not having a *BRCA* test were recorded for the majority (N = 3314; 95.3%) of those without testing (Fig. 1). The two most common reasons for not testing were that the patient was not the best test candidate in the family (N = 930; 28.1%), and that testing was not clinically indicated (N = 773; 23.3%) (Table 2). Together these medical indications for not testing accounted for over half (N = 1703; 51.4%) of those not having testing. Examining those with medical indications for not testing separately from those with non-medical reasons, 86.6% (N = 258) of individuals with breast cancer were not clinically indicated for testing compared to 36.5% (N = 510) of those without a cancer history (Table 3). However, more than half (N = 889; 63.5%) of those without cancer were not the best candidate for testing in the family (Table 3). Patients with a high-risk family history were more frequently classified as not being the best test candidate (N = 507; 78.0%), while those without a family history were more frequently not clinically indicated for testing (N = 630; 59.8%) (Table 3).

Insurance/out of pocket cost concern was the top non-medical reason for not pursuing GT (N = 452; 28.1%) (Table 3) Over one-third of individuals with insurance/out of pocket cost concerns had a high-risk family history, and this proportion did not significantly change over the duration of the study. Individuals with private and government sponsored insurance were equally likely to report insurance/out of pocket

Table 1 Demographics and risk factors of those with and without subsequent *BRCA* testing after genetic counseling, 2008-2012

Characteristic	Did Not Test		Tested		Total		Chi-square p-value*
	N (%)		N (%)		N (%)		
Sex							<0.01
Female	3324	(95.6)	6840	(94.3)	10,164	(94.8)	
Male	152	(4.4)	410	(5.7)	562	(5.2)	
Age							<0.01
Age 50 or under	1844	(53.1)	3573	(49.3)	5417	(50.5)	
Over 50	1632	(47.0)	3677	(50.7)	5309	(49.5)	
Race							<0.01
Asian	60	(1.7)	129	(1.8)	189	(1.8)	
Black or African American	345	(9.9)	466	(6.4)	811	(7.6)	
Other†	232	(6.7)	391	(5.4)	623	(5.8)	
White	2740	(78.8)	6090	(84.0)	8830	(82.3)	
Unknown	99	(2.9)	174	(2.4)	273	(2.6)	
Insurance							0.45
Private	2671	(76.8)	5675	(78.3)	8346	(77.8)	
Government sponsored	683	(19.7)	1374	(19.0)	2057	(19.2)	
None	28	(0.8)	69	(1.0)	97	(0.9)	
Unknown	94	(2.7)	132	(1.8)	226	(2.1)	
Ashkenazi Jewish Ancestry							<0.01
Yes	117	(3.4)	773	(10.7)	890	(8.3)	
No	3359	(96.6)	6477	(89.3)	9836	(91.7)	
Cancer History							<0.01
Breast	1130	(32.5)	4390	(60.6)	5520	(51.5)	
Ovarian	58	(1.7)	314	(4.3)	372	(3.5)	
Both Breast and Ovarian	12	(0.4)	96	(1.3)	108	(1.0)	
None	2276	(65.5)	2450	(33.8)	4726	(44.1)	
High Risk Family History							<0.01
Yes	1281	(36.9)	2978	(41.1)	4259	(39.7)	
No	2195	(63.2)	4272	(58.9)	6467	(60.3)	
Known Mutation in Family							<0.01
Yes	126	(3.6)	1184	(16.3)	1310	(12.2)	
No	3350	(96.4)	6066	(83.7)	9416	(87.8)	
Total	3476	(32.4)	7250	(67.6)	10,726		

*Chi-square statistic omitting missing or 'unknown' values

†includes all multiracial, Native Hawaiian or other Pacific Islander, American Indian or Alaska Native

cost concerns as a barrier to testing (N = 339; 13.4% and N = 91; 13.7% respectively). In addition, 18% (N = 120) of those with government-sponsored insurance did not test because they did not meet Medicare criteria.

All other reasons for not testing comprised less than ten percent of patients who did not test (Table 2). Of note, 17.1% (N = 276) of non-medical abstinence from testing could be attributed to patient disinterest (not a good time, does not want to know, or patient sees no benefit), including 29.8% (N = 28) of patients with a known family mutation who did not test for non-medical reasons (Table 3). While only 1.7% (N = 28) of patients with non-medical reasons cited a desire to arrange life and/or disability insurance prior to GT, 10.6% (N = 10) of patients with a known family mutation with non-medical reasons cited this consideration (Table 3).

Discussion

With the increasing awareness of the availability of GT and the impact of genomic information on medical management, more individuals are presenting to their physicians and genetics professionals for GT with questions about GT, and the potential impact of GT results on personal medical care and the care of family members. Specifically, individuals with germline *BRCA* mutations are known to have elevated cancer

Table 2 Primary reasons for not having *BRCA* testing after genetic counseling

Reason	Number (%)	
Not the best test candidate	930	(28.1)
Not clinically indicated	773	(23.3)
Insurance/out of pocket cost concerns	452	(13.6)
Other reason	429	(12.9)
Discuss options with relatives	210	(6.3)
Does not meet Medicare criteria	133	(4.0)
Not a good time	133	(4.0)
Does not want to know	85	(2.6)
Reassured by risk assessment	83	(2.5)
Patient sees no benefit	58	(1.8)
Arrange life/disability insurance	28	(0.8)
Total	3314	

risks and established screening and surveillance guidelines can reduce cancer related morbidity and mortality in this high-risk population. However, it is known that the majority of breast cancer and familial breast cancer is not due to inherited germline mutations in *BRCA1* and *BRCA2* and germline GT is not indicated in all individuals with personal and/or family histories of *BRCA* related cancer. Understanding the reasons why individuals do not undergo GT following cancer GC and genetic risk assessment may improve the identification of clinically appropriate GT candidates, aid in the appropriate use of GC and GT resources, and ensure that each patient receives appropriate screening and surveillance recommendations based on their personal history, family history and if applicable, GT information.

Emerging data has identified substantial costs associated with "inappropriate" GT ordering practices (Lee 2013; Miller et al. 2014). In our study, over a five-year time period, approximately one-third of the 10,726 patients who underwent *BRCA* GC did not pursue GT. In more than half (51.4%) of these patients, GT was not indicated, either based on risk assessment or because they were not the best test candidate. This underscores the importance of GC and genetic risk assessment to ensure appropriate clinical recommendations are provided to the patient and the family and for the appropriate utilization of health care resources. GC for patients who meet referral criteria, but not GT criteria may be beneficial for a variety of reasons. GC may lead to enhanced awareness about the risk of an inherited cancer predisposition syndrome and personal cancer risks, may provide patients with reassurance, and may encourage communication with appropriate relatives about their option to pursue GT.

The significant number of patients who were referred for GC who did not undergo GT demonstrates the value of GC prior to testing in order to aid in appropriate utilization of GT and medical resources. Understanding the reason why individuals did not pursue GT informs cost-savings initiatives and also identifies educational needs for clinicians and patients. Physician education regarding GT criteria and the importance of initiating GT in the individual within the family with the highest likelihood of carrying a germline mutation is a need identified through this study. Future studies should examine in more detail the exact reasons why GT was not clinically

Table 3 Reasons for not testing by personal and family cancer history, insurance status

Reasons for not Testing	Total	Personal Cancer History				High Risk Family History		Known Mutation in Family	
		Breast	Ovarian	Breast & Ovarian	None	Yes	No	Yes	No
Medically indicated reasons									
Not the best test candidate	930 (54.6)	40 (13.4)	1 (16.7)	–	889 (63.5)	507 (78.0)	423 (40.2)	12 (52.2)	918 (54.6)
Not clinically indicated	773 (45.4)	258 (86.6)	5 (83.3)	–	510 (36.5)	143 (22.0)	630 (59.8)	11 (47.8)	762 (45.4)
Total	1703	298	6	–	1399	650	1053	23	1680
Non-medical reasons									
Insurance/out of pocket cost concerns	452 (28.1)	247 (32.4)	15 (34.1)	5 (41.7)	185 (23.3)	138 (23.9)	314 (30.4)	7 (7.5)	445 (29.3)
Other reason	429 (26.6)	172 (22.6)	9 (20.5)	3 (25.0)	245 (30.9)	182 (31.5)	247 (23.9)	37 (39.4)	392 (25.8)
Patient disinterest[a]	276 (17.1)	149 (19.6)	7 (15.9)	3 (25.0)	117 (14.8)	92 (15.9)	184 (17.8)	28 (29.8)	248 (16.4)
Discuss options with relatives	210 (13.0)	79 (10.4)	8 (18.2)	–	123 (15.5)	89 (15.4)	121 (11.7)	12 (12.8)	198 (13.1)
Does not meet Medicare criteria	133 (8.3)	74 (9.7)	4 (9.1)	1 (8.3)	54 (6.8)	43 (7.5)	90 (8.7)	–	133 (8.7)
Reassured by risk assessment	83 (5.2)	36 (4.7)	1 (2.3)	–	46 (5.8)	17 (3.0)	66 (6.4)	–	83 (5.5)
Arrange life/disability insurance	28 (1.7)	5 (0.7)	–	–	23 (2.9)	16 (2.8)	12 (1.2)	10 (10.6)	18 (1.2)
Total	1611	762	44	12	793	577	1,034	94	1,517

[a] not a good time, does not want to know, and patient sees no benefit

indicated in the 23.3% of the individuals who were not tested and begin to develop resources for patients and clinicians to better identify those who are at the highest risk.

Insurance/out of pocket cost concern continues to be a barrier to appropriate GT, even for those affected with cancer and those with private insurance. Of the 2214 people with private insurance who did not pursue GT, the primary reason for declining testing was insurance/out of pocket cost concerns (15.3%). Insurance/out of pocket cost concerns was a barrier for 36.4% of individuals with government sponsored insurance. The American College of Medical Genetics and Genomics recently published a policy statement challenging payors and health care providers to expand their definition of "clinical utility" and to increase the payor coverage of genetic and genomic testing ("Clinical utility of genetic and genomic services: a position statement of the American College of Medical Genetics and Genomics." 2015). The findings presented here underscore the need to increase coverage of GT for those at elevated risk for hereditary cancer.

In 17.1% of the not tested cohort, 8.4% of the entire cohort of patients who underwent GC, the reason for not testing was "patient disinterest". This category was comprised of "does not want to know", "not a good time", "patient sees no benefit". It is known that many factors can influence a patient's decision to undergo GT including family concerns, fear of adverse psychological consequences, logistic problems, and concerns regarding discrimination as well as demographic characteristics, such as gender and education level (Armstrong et al. 2000; Godard et al. 2007; Goelen et al. 1999; Hallowell et al. 2005; Kieran et al. 2007; Olaya et al. 2009; Thompson et al. 2002). This is an area of future research need as we strive to ensure we are providing patient centric care including addressing concerns and barriers to GT and understanding the right time in a patient's care to engage in a dialogue around GT. These are likely to be based on individual preferences. Future research should further study the needs of this group, and will likely be most informative if combined with the cohort of patients who decline GC.

This study is not without its strengths and limitations. The data collected are from genetics clinics that are supported by a board certified/board eligible cancer genetics specialist. These data may not be representative of the state as a whole and may not reflect the practices and centers that offer GT in the absence of a certified professional. Additionally, each partner clinic functions independently and uniquely. All partner clinics are trained on data collection and all attempts to standardize reporting are made, however the primary reason why an individual does not pursue GT is selected by the genetic provider in each independent center. How each center and each genetic provider identifies the primary reason may be different and may not be consistent with the primary reason a patient may select. Future studies should explore these limitations. The study utilized a state-wide database, encompassing all regions of the state of Michigan. The large sample size allowed for ample collection of data on the reasons for not pursuing GT. Providers were given the option to free text write in if the reason was not one of the commonly selected, permitting further flexibility in describing the clinical scenario.

In summary, this study is the largest public health surveillance program exploring *BRCA* GT in the United States. In this large, prospective, multi-center study, nearly one-third of patients did not pursue GT following GC and risk assessment. The leading factors, GT was not clinically indicated and the presenting individual was not the best person in whom to initiate GT, highlight the value of GC and the importance of a clinical genetics risk assessment prior to undergoing GT. Additionally, insurance coverage and out of pocket cost continue to be barriers to GT, even in those with private insurance. Continued understanding of the definition of "clinical utility" and demonstration of the multiple definitions of "value" in GT can aid in addressing this GT barrier.

Acknowledgements The Michigan BRCA Clinical Partners Network Publications Group including (in alphabetical order): Kristen Hanson, MS; Sarah Keilman, MS; Sofia Merajver, MD; Kara Milliron, MS; Dana Zakalik, MD; Julie Zenger Hain, PhD

The Michigan BRCA Clinical Partners Network including the following institutional partners (in alphabetical order): Beaumont Cancer Genetics Program, Cancer Genetics Program at St. Joseph Mercy Hospital, Henry Ford Health System, InformedDNA, Karmanos Cancer Genetic Counseling Service, Lacks Cancer Center Genetics Program at St. Mary's Healthcare, Marquette General Hereditary Cancer Program, Michigan State University Division of Clinical Genetics, MidMichigan Health Cancer Genetics Program, Oakwood Healthcare System's Genetic Risk Assessment for Cancer Clinic, Providence Hospital Medical Genetics, Spectrum Health Cancer Genetics, University of Michigan – Cancer Genetics Clinic, University of Michigan – Breast and Ovarian Cancer Risk and Evaluation Program, West Michigan Cancer Center

Compliance with Ethical Standards

Funding This publication was supported by the Cooperative Agreement Numbers 5U38GD00054 and 51U58DP003798 from The Centers for Disease Control and Prevention. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the Centers for Disease Control and Prevention

Conflict of Interest Sommer Hayden, Sarah Mange, Debra Duquette, Nancie Petrucelli and Victoria M. Raymond declare that they have no conflict of interest.

Disclosures Victoria M. Raymond is a full time employee of Trovagene, Inc

Ethical Approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed Consent These data are consistent with public health surveillance and not research as defined by the code of federal regulations (CFR) 46.102 (D) and therefore were deemed exempt by the Michigan Department of Health and Human Services (MDHHS) Institutional Review Board (IRB) for the Protection of Human Research Subjects. The collaborative project was reviewed by the IRB's of each individual institution.

Animal Studies No animal studies were carried out by the authors for this article.

References

U.S. Preventive Services Task Force (2005). Genetic risk assessment and BRCA mutation testing for breast and ovarian cancer susceptibility: recommendation statement. *Annals of Internal Medicine*, *143*(5), 355–61. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/16144894

ACMG Board of Directors (2015). Clinical utility of genetic and genomic services: a position statement the American College of Medical Genetics and Genomics. *Genetics in Medicine: Official Journal of the American College of Medical Genetics and Genomics, 17*, 505–507.

Armstrong, K., Calzone, K., Stopfer, J., Fitzgerald, G., Coyne, J., & Weber, B. (2000). Factors associated with decisions about clinical BRCA1/2 testing. *Cancer Epidemiology, Biomarkers & Prevention : A Publication of the American Association for Cancer Research, Cosponsored by the American Society of Preventive Oncology*, *9*(11), 1251–4. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/11097234

Borzekowski, D. L. G., Guan, Y., Smith, K. C., Erby, L. H., & Roter, D. L. (2014). The Angelina effect: immediate reach, grasp, and impact of going public. *Genetics in Medicine : Official Journal of the American College of Medical Genetics, 16*(7), 516–521. doi:10.1038/gim.2013.181.

Chen, S., & Parmigiani, G. (2007). Meta-analysis of BRCA1 and BRCA2 penetrance. *Journal of Clinical Oncology : Official Journal of the American Society of Clinical Oncology, 25*(11), 1329–1333. doi:10.1200/JCO.2006.09.1066.

Chen, S., Iversen, E. S., Friebel, T., Finkelstein, D., Weber, B. L., Eisen, A., … Parmigiani, G. (2006). Characterization of BRCA1 and BRCA2 mutations in a large United States sample. *Journal of Clinical Oncology : Official Journal of the American Society of Clinical Oncology*, *24*(6), 863–71. doi:10.1200/JCO.2005.03.6772

Claus, E. B., Schildkraut, J. M., Thompson, W. D., & Risch, N. J. (1996). The genetic attributable risk of breast and ovarian cancer. *Cancer, 77*(11), 2318–2324. doi:10.1002/(SICI)1097-0142(19960601)77:11<2318::AID-CNCR21>3.0.CO;2-Z.

Domchek, S. M., Armstrong, K., & Weber, B. L. (2006). Clinical management of BRCA1 and BRCA2 mutation carriers. *Nature Clinical Practice. Oncology, 3*(1), 2–3. doi:10.1038/ncponc0384.

Godard, B., Pratte, A., Dumont, M., Simard-Lebrun, A., & Simard, J. (2007). Factors associated with an individual's decision to withdraw from genetic testing for breast and ovarian cancer susceptibility: implications for counseling. *Genetic Testing, 11*(1), 45–54. doi:10.1089/gte.2006.9998.

Goelen, G., Rigo, A., Bonduelle, M., & De Grève, J. (1999). Moral concerns of different types of patients in clinical BRCA1/2 gene mutation testing. *Journal of Clinical Oncology : Official Journal of the American Society of Clinical Oncology*, *17*(5), 1595–600. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/10334549

Hallowell, N., Ardern-Jones, A., Eeles, R., Foster, C., Lucassen, A., Moynihan, C., & Watson, M. (2005). Men's decision-making about predictive BRCA1/2 testing: the role of family. *Journal of Genetic Counseling, 14*(3), 207–217. doi:10.1007/s10897-005-0384-3.

Hartmann, L. C., Schaid, D. J., Woods, J. E., Crotty, T. P., Myers, J. L., Arnold, P. G., … Jenkins, R. B. (1999). Efficacy of bilateral prophylactic mastectomy in women with a family history of breast cancer. *The New England Journal of Medicine*, *340*(2), 77–84. doi:10.1056/NEJM199901143400201

Hartmann, L. C., Sellers, T. A., Schaid, D. J., Frank, T. S., Soderberg, C. L., Sitta, D. L., … Jenkins, R. B. (2001). Efficacy of bilateral prophylactic mastectomy in BRCA1 and BRCA2 gene mutation carriers. *Journal of the National Cancer Institute*, *93*(21), 1633–7. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/11698567

Kieran, S., Loescher, L. J., & Lim, K. H. (2007). The role of financial factors in acceptance of clinical BRCA genetic testing. *Genetic Testing, 11*(1), 101–110. doi:10.1089/gte.2006.9999.

King, M.-C., Marks, J. H., & Mandell, J. B. (2003). Breast and ovarian cancer risks due to inherited mutations in BRCA1 and BRCA2. *Science (New York, N.Y.), 302*(5645), 643–646. doi:10.1126/science.1088759.

Lee, J. (2013). Cigna requires genetic counseling to end inappropriate testing. *Modern Healthcare*. Retrieved from http://www.modernhealthcare.com/article/20130727/MAGAZINE/307279986

Mai, P. L., Vadaparampil, S. T., Breen, N., McNeel, T. S., Wideroff, L., & Graubard, B. I. (2014). Awareness of cancer susceptibility genetic testing: the 2000, 2005, and 2010 National Health Interview Surveys. *American Journal of Preventive Medicine, 46*(5), 440–448. doi:10.1016/j.amepre.2014.01.002.

Miller, C. E., Krautscheid, P., Baldwin, E. E., Tvrdik, T., Openshaw, A. S., Hart, K., & Lagrave, D. (2014). Genetic counselor review of genetic test orders in a reference laboratory reduces unnecessary testing. *American Journal of Medical Genetics. Part A, 164A*(5), 1094–1101. doi:10.1002/ajmg.a.36453.

Olaya, W., Esquivel, P., Wong, J. H., Morgan, J. W., Freeberg, A., Roy-Chowdhury, S., & Lum, S. S. (2009). Disparities in BRCA testing: when insurance coverage is not a barrier. *American Journal of Surgery, 198*(4), 562–565. doi:10.1016/j.amjsurg.2009.07.003.

Pal, T., Permuth-Wey, J., Betts, J. A., Krischer, J. P., Fiorica, J., Arango, H., … Sutphen, R. (2005). BRCA1 and BRCA2 mutations account for a large proportion of ovarian carcinoma cases. *Cancer*, *104*(12), 2807–16. doi:10.1002/cncr.21536

Rebbeck, T. R., Kauff, N. D., & Domchek, S. M. (2009). Meta-analysis of risk reduction estimates associated with risk-reducing salpingo-oophorectomy in BRCA1 or BRCA2 mutation carriers. *Journal of the National Cancer Institute, 101*(2), 80–87. doi:10.1093/jnci/djn442.

Ropka, M. E., Wenzel, J., Phillips, E. K., Siadaty, M., & Philbrick, J. T. (2006). Uptake rates for breast cancer genetic testing: a systematic review. *Cancer Epidemiology, Biomarkers & Prevention : A Publication of the American Association for Cancer Research, Cosponsored by the American Society of Preventive Oncology, 15*(5), 840–855. doi:10.1158/1055-9965.EPI-05-0002.

Saslow, D., Boetes, C., Burke, W., Harms, S., Leach, M. O., Lehman, C. D., … Russell, C. A. (2007). American Cancer Society guidelines for breast screening with MRI as an adjunct to mammography. *CA: A Cancer Journal for Clinicians*, *57*(2), 75–89. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/17392385

Thompson, H. S., Valdimarsdottir, H. B., Duteau-Buck, C., Guevarra, J., Bovbjerg, D. H., Richmond-Avellaneda, C., … Offit, K. (2002). Psychosocial predictors of BRCA counseling and testing decisions among urban African-American women. *Cancer Epidemiology, Biomarkers & Prevention : A Publication of the American Association for Cancer Research, Cosponsored by the American Society of Preventive Oncology*, *11*(12), 1579–85. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/12496047