Reasons for Declining BRCA Testing After Genetic Counseling

Sarah Mange*, MPH, Nancie Petrucelli†, MS, CGC, Dana Zakalik‡, MD, Deb Duquette*, MS, CGC

*Michigan Department of Community Health, Division of Genomics, Perinatal Health and Chronic Disease Epidemiology; †Karmanos Cancer Institute; ‡Beaumont Hospital

Background

As part of a cooperative agreement with the Centers for Disease Control and Prevention (CDC), the Michigan Department of Community Health (MDCH) Cancer Genomics Program maintains a surveillance database with de-identified visit and testing information on all patients seen for BRCA genetic counseling by a board-certified genetics professional in Michigan. These data are used to measure both the United States Preventive Services Task Force (USPSTF) 2005 recommendation for genetic counseling and risk evaluation based on family history[1] as well as the *Healthy People 2020* Goal G-1[2] in Michigan.

HP2020 Goal G-1

Increase the proportion of women with a family history of breast and/or ovarian cancer who receive genetic counseling

Genetic counseling promotes accurate risk assessment and appropriate, informed genetic testing with applicable follow-up care and screenings. However, genetic testing may not be indicated for all patients, and some patients have internal or external barriers to appropriate testing. Previous studies have shown that affordability, family concerns, and fear of discrimination all influence testing decisions.[3,4]

Objectives

- To determine the primary reasons for declining BRCA testing after genetic counseling
- To describe the patient populations with barriers to BRCA testing after accessing genetic counseling
- To describe the impact of genetic counseling in avoiding unnecessary/inappropriate BRCA testing

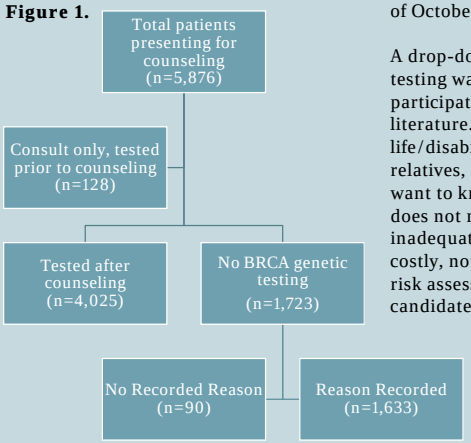
Methods

Cancer Genetics clinics participating in the MDCH network collected data on all patients seen for genetic counseling within the period of October 1, 2007 to March 31, 2011.

A drop-down menu of reasons for declining testing was created with input from participating providers after consulting the literature. These reasons include: arrange life/disability insurance, discuss options with relatives, patient sees no benefit, does not want to know genetic status, not a good time, does not meet Medicare criteria for coverage, inadequate insurance coverage, test co-pay too costly, not clinically indicated, reassured by risk assessment, and not the best test candidate in the family.

Patients who presented to counseling without prior testing and with a recorded reason for not testing were included in this analysis (n = 1,633).

Figure 1.



1. US Preventive Services Task Force. Genetic Risk Assessment and BRCA Mutation Testing for Breast and Ovarian Cancer Susceptibility: Recommendation Statement. Ann Intern Med 2005 Sep 6; 143:355-361.
2. Healthy People 2020, Objective G HP2020. Accessed March 22, 2012. http://www.healthypeople.gov/2020/topicsobjectives2020/pdfs/Genomics.pdf
3. Armstrong K., et al. Factors associated with decisions about clinical BRCA1/1 testing. Cancer Epidemiol. Biomark. Prev., 9:1251-1254, 2000.
4. Peterson E., et al. Health insurance and discrimination concerns and BRCA1/2 testing in a clinic population. Cancer Epidemiol. Biomark. Prev., 11:79-87, 2002

Results

Nearly one-third (1,723, 30.0%) of patients presenting for genetic counseling without previous testing did not proceed with BRCA testing. Reasons for not testing were recorded for 1,633 (94.8%) of these patients.

Table 1. Reasons for declining BRCA genetic testing after receiving genetic counseling

Reason	Number (%)
Not the best test candidate	477 (29.2)
Not clinically indicated	436 (26.7)
Inadequate insurance coverage	243 (14.9)
Other	117 (7.2)
Discuss options with relatives	80 (4.9)
Not a good time	71 (4.4)
Reassured by risk assessment	50 (3.1)
Does not meet Medicare criteria	45 (2.8)
Does not want to know	45 (2.8)
Test co-pay too costly	30 (1.8)
Patient sees no benefit	20 (1.2)
Arrange life/disability insurance	19 (1.2)
Total	1,633

Table 1. Over half of all patients declining testing would either benefit from a more informative test strategy of testing a relative affected with cancer first (not the best test candidate, 29.2%) or testing was inappropriate based on low risk (not clinically indicated and reassured by risk assessment, 29.8%). Inadequate health insurance coverage* (see upper right for included categories) was the top barrier to potentially appropriate testing (19.5%) followed by a number of personal hesitations† (13.2%).

Table 2. Characteristics of Patients With Selected Barriers to Testing

	Inadequate Health Insurance Coverage* N (%)	Personal Hesitation† N (%)
USPSTF Family History		
No	221 (69.5)	130 (60.2)
Yes	97 (30.5)	86 (39.8)
Personal Cancer History		
No	117 (36.8)	91 (42.1)
Yes	201 (63.2)	125 (57.9)
Ashkenazi Jewish		
No	307 (96.5)	201 (93.1)
Yes	11 (3.5)	15 (6.9)
Known Familial Mutation		
No	315 (99.1)	200 (92.6)
Yes	3 (0.9)	16 (7.4)
Insurance Type		
Private‡	252 (79.2)	205 (94.9)
Medicare/Medicaid‡	91 (28.6)	28 (13.0)
None	10 (3.1)	2 (4.6)
Total	318	216

*Includes inadequate insurance coverage, test co-pay too costly, and does not meet Medicare criteria for coverage

†Includes discuss options with relatives, not a good time, does not want to know genetic status, and patient sees no benefit

‡Includes patients with both private insurance and Medicare/Medicaid coverage

Table 2. While only 3.1% of patients with health insurance barriers did not have insurance, 308 patients could not afford testing at their level of insurance coverage, including 91 (28.6%) with Medicare/Medicaid coverage. Other patients decline testing because of personal hesitation in spite of risk factors such as personal and family history, including 16 patients with a known familial mutation, the highest level of risk.

Conclusion

These reasons for declining testing can be conceptualized as a continuum ranging from inappropriate to appropriate with internal or external barriers. Inappropriate testing includes those with low risk (not clinically indicated, reassured by risk assessment) or those benefiting from another test strategy (not the best test candidate). These patients may become appropriate for testing depending on their relative's test results. More information is needed about those concerned with life/disability insurance, which is potentially either an internal and external barrier. Barriers to appropriate testing can be external, such as health insurance and affordability, or internal personal hesitations.

This data demonstrates the importance of:

1) Avoiding inappropriate BRCA testing through genetic counseling and risk assessment
2) The need for guidelines that emphasize testing affected relatives prior to testing unaffected relatives
3) Inadequate insurance coverage as a barrier for patients who would benefit from such testing
4) The need for better understanding of the personal barriers to testing in those at high risk of mutation

Acknowledgements

Special thanks to our contributing clinical partners: Beaumont Hospital, Henry Ford Health System, Informed Medical Decisions Inc., Karmanos Cancer Institute, Michigan State University, Oakwood Hospital, Providence Hospital and Medical Centers, Spectrum Health System, University of Michigan Cancer Genetics Clinic, University of Michigan Breast and Ovarian Cancer Risk and Evaluation Program

This project is supported by Cooperative Agreement # 1U58DP003798-01 from the Centers for Disease Control and Prevention (CDC). Its contents are solely the responsibility of the authors and do not necessarily represent the official views of CDC.