MICHIGAN BRFSS SURVEILLANCE BRIEF

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Cancer Family History and Genetic Counseling & Testing

Harmful mutations in the breast cancer genes (*BRCA1* and *BRCA2)* are associated with Hereditary Breast and Ovarian Cancer (HBOC), a syndrome which substantially increases the risk of developing breast, ovarian, pancreatic, prostate and other cancers over the course of a lifetime.[1] A strong history of breast and/or ovarian cancer in families means a person is more likely to have HBOC. Variations in *MLH1*, *MSH2*, *MSH6*, *PMS2*, or *EPCAM* genes increase the risk of developing Lynch syndrome (LS). LS is an inherited disorder that increases the risk of colorectal, endometrial, ovarian, stomach, liver, kidney, brain, and certain types of skin cancers, and more often these cancers are diagnosed at a younger age.[2] A strong history of colorectal cancer in families means a person will be more likely to have LS. It is important to collect family health history to determine if your risk of breast, ovarian, colorectal or endometrial cancer is higher than the general public.

Background

HBOC causes approximately 7,500 breast cancer and 2,000 ovarian cancer cases per year in the United States.[1] LS causes approximately 4,000 colorectal cases per year in the United States.[2] The National Comprehensive Cancer Network (NCCN) recommends that women with a strong family history of breast and ovarian cancer should pursue genetic counseling and testing.[3] The NCCN recommends that all newly diagnosed colorectal cancer cases be referred for tumor genetic testing for characteristics of LS, especially for individuals diagnosed with colorectal cancer before 50 years and those with a significant family history of colorectal cancer to be evaluated for LS.[3] This surveillance brief explores how family history of these cancers are discussed in a health care setting and the prevalence of cancer genetic counseling and testing in 2020.

Methods

Questions related to breast, ovarian, colorectal, and endometrial cancer family history and genetic counseling and testing were included within the 2020 Michigan Behavioral Risk Factor Survey. This data was used to analyze the prevalence of cancer family history and how this is discussed in a health care setting among adults in Michigan and assess the utilization of cancer genetic counseling and testing among these adults. The cancer family history questions asked about diagnoses of these cancers among their biological relatives; an additional question determined if these individuals were asked about their family history via a form and whether they discussed this information with a health care provider. Furthermore, genetic counseling was defined as the process of communication between a health professional who is trained in genetics and someone concerned about the risk of disease in his or her family. Genetic testing was defined as the process of submitting a blood or saliva sample to test if a person had a genetic mutation in a cancer-causing gene.

What is the Michigan Behavioral Risk Factor Surveillance System (MiBRFSS)?

The MiBRFSS comprises annual, statewide telephone surveys of Michigan adults aged 18 years and older and is part of the national BRFSS coordinated by the CDC. The MiBRFSS follows the CDC BRFSS protocol and uses the standardized English core questionnaire that focuses on various health behaviors, medical conditions, and preventive health care practices related to the leading causes of mortality, morbidity, and disability. Landline and cell phone interviews are conducted across each calendar year. Data is weighted to adjust for the probabilities of selection and a raking weighting factor is used to adjust for the distribution of the Michigan adult population based on eight demographic variables. All analyses are performed using SAS-callable SUDAAN® to account for the complex sampling design.

Results

In 2020, 66.9% of respondents reported they had a family history of breast cancer, 16.5% a family history of ovarian cancer, 84.8% a family history of colorectal cancer and 9.0% a family history of endometrial cancer (Table 1). Out of all adults surveyed in 2020, 87.3% were asked about their family history of cancer either in a medical visit or on a form while only 56.9% discussed their family history and personal risk of cancer with a health care provider. Only 11.9% of respondents indicated that they or a family member received genetic counseling for hereditary cancer, and 11.7% indicated that they or a family member received genetic testing (Table 1).

Table 1. Family History of Cancer, BRFSS 2020

	Frequency	Percent	95% CI
Relatives diagnosed with breast or ovarian cancer			
Breast cancer only	4,649,148	66.9	65.0-68.7
Ovarian cancer only	1,148,558	16.5	15.1-18.0
Breast and ovarian cancer	563,193	8.1	7.1-9.2
Breast or ovarian cancer*	462,525	6.7	5.7-7.7
Relatives diagnosed with colorectal or endometrial cancer			
Colorectal cancer only	5,822,870	84.8	83.4-86.1
Endometrial cancer only	619,929	9.0	8.1-10.1
Colorectal and endometrial cancer	118,704	1.7	1.3-2.3
Colorectal or endometrial cancer*	26,194	0.4	0.2-0.6
Asked about family history			
Yes	6,117,229	87.3	85.8-88.6
Discussed family history with a health care provider			
Yes	3,993,509	56.9	54.9-58.8
Genetic counseling for hereditary cancer			
Yourself only	159,869	2.3	1.9-2.9
At least one family member	432,436	6.3	5.4-7.4
Yourself and at least one family member	226,324	3.3	2.7-4.0
No one	6,044,857	88.1	86.7-89.3
Genetic testing for hereditary cancer			
Yourself	152,104	2.2	1.7-2.9
At least one family member	504,289	7.4	6.5-8.5
Yourself and at least one family member	144,703	2.1	1.6-2.8
No one	5,980,618	88.2	86.9-89.4

*It was discovered that due to a programming error, two categories shared the same value for two questions: (1) the knowledge of family cancer history involving breast/ovarian cancer and (2) colorectal/endometrial cancer. If the respondent had reported only one of these (either breast or ovarian cancer, or only colorectal or endometrial cancer), the same value was stored, regardless of whether it was breast or ovarian or colorectal or endometrial cancer. Upon discovery of the problem, all impacted cases were identified, and review of the interview recordings proceeded to recover the correct response. Unfortunately, due to converting a portion of the interviewing staff to remote calling because of COVID, not all cases have recordings. Cases for which recordings were not available were identified and respondents were called back to collect the missing data. Of the 1,191 cases identified to have at least one of the questions impacted, 802 (67.3%) were able to be corrected through listening to recordings or calling back the respondent. Responses were recorded into a new category for cases where the responses could not be corrected.

Table 2. Discussing Family History and Genetic Counseling and Testing among Respondents who Have a Family History of Cancer, BRFSS 2020

	Family History of Breast Cancer			Family History of Ovarian Cancer			Family History Colorectal Cancer		
	Frequency	Percent	95% CI	Frequency	Percent	95% CI	Frequency	Percent	95% CI
Asked about family history									
Yes	1,043,534	93.1	90.3-95.1	~	~	~	~	~	~
Discussed family history with a health care provider									
Yes	777,215	**68.6**	64.0-72.9	407,565	72.4	65.8-78.2	484,464	**79.2**	74.1-83.6
Genetic counseling for hereditary cancer									
Yourself only	41,966	3.8	2.5-5.7	27,822	5.2	3.0-9.0	26,215	4.4	2.7-7.2
At least one family member	132,439	11.9	9.0-15.5	86,002	16.1	11.6-22.0	60,634	10.3	7.0-14.7
Yourself and at least one family member	46,022	4.1	2.8-6.0	53,904	10.1	6.5-15.5	36,688	6.5	3.9-10.7
No one	895,445	**80.2**	76.3-83.7	365,451	**68.5**	61.6-74.7	465,423	**78.8**	73.2-83.4
Genetic testing for hereditary cancer									
Yourself	38,972	3.5	2.3-5.5	28,565	5.4	3.1-9.3	19,015	3.2	1.8-5.6
At least one family member	156,854	14.3	11.4-17.8	73,097	13.8	9.4-19.7	73,861	12.5	8.9-17.2
Yourself and at least one family member	26,079	2.4	1.5-3.6	27,264	5.1	3.0-8.7	17,014	2.9	1.6-5.2
No one	876,262	79.8	76.0-83.1	402,060	75.7	69.2-81.2	483,046	81.5	76.4-85.7

CI = confidence interval.

- Data is suppressed when sample frequencies are less than 50 and/or a relative standard error is greater than 30%.

* Bold number indicates the prevalence of family history among that specific group was significantly different compared to other groups.

There were several significant differences in discussing family history and receiving genetic counseling and testing based on family history of cancer (Table 2). Those with a family history of colorectal cancer were more likely to discuss their family history of cancer with a health care provider compared to those with a family history of breast cancer (79.2% vs. 68.6%). Those with a family history of ovarian cancer were the most likely to have themselves or a family member receive genetic counseling compared to those with a family history of breast cancer (31.4% vs. 19.8%). Those with a family history of colorectal cancer were most likely to not have themselves or a family member receive genetic testing compared to those with a family history of ovarian cancer (81.5% vs. 75.7%); however, this difference was not statistically significant.

Table 3. Genetic Counseling and Testing among Respondents who were Asked and Discussed Their Family History of Cancer, BRFSS 2020

	Asked about Family History			Discussed Family History		
	Frequency	Percent	95% CI	Frequency	Percent	95% CI
Genetic counseling for hereditary cancer						
Yourself only	159,452	2.7	2.2-3.4	153,567	4.0	3.2-5.0
At least one family member	408,999	6.9	5.9-8.1	346,321	9.0	7.6-10.7
Yourself and at least one family member	224,195	3.8	3.1-4.6	211,673	5.5	4.5-6.8
No one	5,115,703	**86.6**	85.1-88.0	3,124,612	**81.5**	79.3-83.4
Genetic testing for hereditary cancer						
Yourself	150,892	2.6	2.0-3.3	138,679	3.6	2.8-4.6
At least one family member	464,065	7.9	6.9-9.1	359,215	9.3	8.0-10.9
Yourself and at least one family member	139,442	2.4	1.8-3.1	129,689	3.4	2.5-4.5
No one	5,093,985	**87.1**	85.6-88.4	3,221,615	**83.7**	81.7-85.5

CI = confidence interval.

- Data is suppressed when sample frequencies are less than 50 and/or a relative standard error is greater than 30%.

* Bold number indicates the prevalence of family history among that specific group was significantly different compared to other groups.

There were significant differences in genetic counseling and testing based on whether the respondent was asked or discussed their family history of cancer with a health care provider (Table 3). Those who discussed their family history with a health care provider were less likely to have no one in their family, including themselves, receive both counseling and testing compared to those who were only asked about their family history via a form or application. Of those who were asked about their family history of cancer, 64.6% discussed this family history with a provider, 13.4% received genetic counseling and 12.9% received genetic testing (data not shown). Of those who discussed their family history of cancer with a provider, 16.3% received genetic testing, which was significantly greater compared to those who were only asked about family history, and 18.5% received genetic counseling, which was significantly greater compared to those who were only asked about family history. Additionally, 11.9% had themselves or a family member receive genetic counseling, and 11.8% had genetic testing. Only 45.2% of those who had counseling reported (either themselves, a family member, or a combination of both) also having genetic testing performed (data not shown).

Discussion

Even though 90-97% of those with family history, regardless of type, were asked about their family history, less than 80% of individuals reported discussing this risk with a health care provider. It is important to note that these individuals should be referred to genetic counseling and testing, as NCCN guidelines suggest that those with family history of these cancer types are at an increased risk of cancer. Genetic counseling with a board certified and/or eligible genetics provider, followed by genetic testing as appropriate, are the recommended first steps for anyone with a personal history or strong family history of these cancers. Early identification of HBOC and LS can help reduce the impact of cancer and save the lives of family members who may also be at risk.

To assist health care providers in determining if genetic services would benefit a patient, the Cancer Genomics Program has been involved in several projects promoting provider education for hereditary cancer management. The Cancer Genomics Program has established a workgroup of genetic counselors to document key points for health care providers to consider before ordering genetic testing. The goal of this project is to help health care providers navigate genetic testing options and encourage shared decision making with their patients. Hereditary cancer education will also be promoted on MDHHS social media pages, highlighting CME opportunities available for providers. In collaboration with the Program for Breast Cancer in Young Women, a webinar was hosted to assist health care providers in identifying

patients at risk for hereditary cancers and how hereditary cancer syndromes can change clinical management of a patient and increase cancer risk for a patient's family members. These targeted initiatives will help health care providers better evaluate patients at risk for hereditary cancer syndromes.

References

1. Breast Cancer Prevention Partners [BCPP] (2021). African American Women and Breast Cancer. Retrieved September 2021 from: https://www.bcpp.org/resource/african-american-women-and-breast-cancer/

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3. National Comprehensive Cancer Network (NCCN) Guidelines for Detection, Prevention, & Risk Reduction (2021). Genetic/Familial High-Risk Assessment: Breast, Ovarian, and Pancreatic. September 2021 from: https://www.nccn.org/guidelines/guidelines-detail?category=2&id=1436.

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