

# Utilization of Cancer Genetic Services by Young Female Breast Cancer Survivors

Beth Anderson<sup>†</sup>, MPH, Jenna McLosky<sup>†</sup>, MS, CGC, Elizabeth Wasilevich<sup>†</sup> PhD, MPH, Sarah Lyon-Callo<sup>†</sup> MA, MS  
 Debra Duquette<sup>†</sup>, MS, CGC and Glenn Copeland<sup>†</sup> MBA



## INTRODUCTION

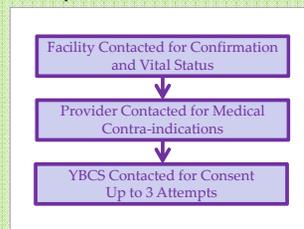
Breast cancer diagnosed at a young age is an indication of a higher risk for inherited cancer syndromes, such as hereditary breast and/or ovarian cancer syndrome (HBOC) [1,2,3]. According to the recently published National Comprehensive Cancer Network (NCCN) Guidelines, women diagnosed with breast cancer prior to age 50 should be referred for further risk assessment, genetic counseling, and possible genetic testing [3].

**Objective**  
 To examine the number of YBCS who have been referred for cancer genetic services and to determine the self-reported barriers and facilitators to receiving these services, within a representative state cancer registry sample

## METHODS

The sampling frame included 500 women between the ages 18-49 who were diagnosed with breast cancer in the years 2006 or 2007 in the state of Michigan. The eligible population was selected from the Michigan Cancer Surveillance Program (MCSP) registry which has a mandate to collect data from local reporting facilities on all cases of cancer and other specified tumorous and precancerous diseases that occur in the state. Women who were known to be deceased were excluded. Prior to implementation, the Michigan Department of Community Health's Institutional Review Board and the MCSP's Scientific Advisory Board reviewed and approved the study.

Figure 1. Flow chart of the selection and consent process



### Selection and Consent Process

The selection process consisted of three steps based on an existing standard method used by MCSP (Figure 1). If the local reporting facility and diagnosing physician did not object to MCSP contacting their patient, the participant was mailed the survey with up to three attempts. The respondent was asked to sign an informed consent attached to the survey.

The self-administered paper-based survey contained questions on demographics, family history of breast and ovarian cancer, genetic testing and counseling, and facilitators and barriers to obtaining genetic services. Participants who returned a signed consent and survey were mailed a \$10 gift card.

### Survey Questions on Facilitators and Barriers

- Please tell us why you decided to go for cancer genetics services
- Please tell us what factors made it easier for you to go for cancer genetics services
- Please tell us why you have not had cancer genetics services

\*Questions were closed-ended. Response options can be seen in Tables 1 and 2

Response frequencies were assessed for differences between groups defined by demographic characteristics, socioeconomic characteristics, and family history of cancer. Two-sided Pearson Chi-Square tests were used to determine significant differences between subpopulations; p-values of <0.05 were considered statistically significant.

## REFERENCES

1. Ruddy, KJ, Gelber, S, Garber, et al. Genetic testing in young women with breast cancer: results from a web-based survey. *Ann Oncol* 2010;21:741-47.
2. U.S. Preventive Services Task Force: Genetic Risk Assessment and BRCA Mutation Testing for Breast and Ovarian Cancer Susceptibility: Recommendation Statement. *Ann Intern Med* 2005; 143(5):355-361.
3. National Comprehensive Cancer Network Clinical Practice Guidelines in Oncology. "Genetic/Familial High-Risk Assessment: Breast and Ovarian." Version 1.2011. Retrieved February 2012, from <http://www.nccn.org/idx.asp>.
4. Bellcross, CA, Kolor, K, et al. Awareness and Utilization of BRCA1/2 Testing Among U.S. Primary Care Physicians. *Am J Prev Med* 2011; 40(1):61-66.

<sup>†</sup>The Michigan Department of Community Health  
<sup>†</sup>Blue Cross Blue Shield of Michigan

This project is supported by Cooperative Agreement # 5U38GD000054 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.

## RESULTS

Twelve women were determined to be ineligible for the study (five who were deceased and seven with medical contraindications). Surveys and consent documents were sent to the remaining 488 women in the sample. Response rate was 59.2% (n=289). The response rate from the black population (35.8%) was significantly lower than the response rate from the white population (64.0%), (p<0.001).

Respondents were primarily white (86.2%), employed for wages (56.1%) and had private insurance (75.4%). One-hundred and twenty-two respondents (42.2%) reported receiving cancer genetic services. Compared to those who did not receive cancer genetic services, the women who received services were of a younger age, higher education and more likely to have family history of breast and/or ovarian cancer.

### Facilitators

The most frequently cited reasons for going to genetic services were 'benefit my family's future' (86.1%), followed by 'wanted to know my future risk of cancer' (50.8%) (Table 1).

The top factors for YBCS that made it easier were 'medical insurance covered the visit' (68.0%), 'the clinic was close to home' (40.2%), and 'have available transportation' (40.2%) (Table 1).

Importantly, 121 of the 122 women who received the cancer genetic services were told or recommended to go by a health care professional or family member. The majority were told by an oncologist (48.4%) or surgeon (19.7%), with OB/GYN (4.9%), genetic counselor (4.9%) or family member (4.9%) less frequently mentioned.

Table 1. Reasons for going to cancer genetic services and factors that made it easier

Reasons for going	N=122 (42.2%)
Benefit my family's future	105 (86.1%)
Wanted to know my future risk of cancer	62 (50.8%)
My doctor recommended that I go	50 (41.0%)
May alter my cancer treatment	48 (39.3%)
Going seemed very important	41 (33.6%)
Family members wanted me to go	21 (17.2%)
Already knew of a familial mutation	3 (2.5%)
Factors that made it easier to go	N=122 (42.2%)
My medical insurance covered the visit	83 (68.0%)
Clinic was close to home	49 (40.2%)
Have available transportation	49 (40.2%)
Clinic hours were flexible and fit my schedule	30 (24.6%)
Have available childcare	11 (9.0%)
I was able to obtain these services by phone	2 (1.6%)

### Barriers

The top barriers reported were 'no one ever recommended it' (58.2%), 'medical insurance coverage issues' (23.4%), and 'did not know they existed' (10.8%), (Table 2).

Among the 37 women who did not receive genetic services and reported medical insurance coverage issues, 62.2% had private insurance.

Additionally, among the 158 women who did not receive cancer genetic services, 72.9% were never told to or recommended to go to cancer genetic services by anyone. Trouble keeping follow up cancer treatment appointments was more frequent among women who did not receive cancer genetic services (14.6%) than women who did receive cancer genetic services (8.2%).

Table 2. Reasons for not having cancer genetic services

Reasons for not going	N=158 (54.7%)
No one ever recommended it	92 (58.2%)
Medical insurance coverage issues	37 (23.4%)
Did not know they existed	17 (10.8%)
Worried a genetic test could be used against me	15 (9.5%)
Too nervous	6 (3.8%)
A doctor told me not to go	5 (3.2%)
Lack of transportation	4 (2.5%)
Other life issues arise that are more important	4 (2.5%)
Too busy	3 (1.9%)
Disability makes it difficult to carry out daily activities	2 (1.3%)
Family members wouldn't want me to go	2 (1.3%)

## DISCUSSION

This is the first study that provides community-based information about barriers and facilitators to obtaining genetic services among YBCS. The role of a healthcare provider has been shown to be a strong facilitator for receiving cancer genetic services and was seen as the third most noted facilitator in this study. Approximately three-quarters of the Michigan YBCS who were told to go to cancer genetic services followed through with this recommendation. It was also seen as the top barrier with over half of the YBCS noting 'no one recommended it'. A recent survey of primary care physicians showed that 87% were aware of BRCA genetic testing however, less than one-fifth were able to correctly identify low and high risk clinical scenarios[4].

### Conclusions and Implications:

- Healthcare providers have an influential role in motivating patients to receive cancer genetic services
- There is a need for promotion and education outreach to providers on the national guidelines and importance for referral to genetic services
- Policies to improve use and access to cancer genetic services need to be explored and initiated to help detect cancer earlier and reduce mortality