Breast and Ovarian Cancer Risk Management Practices Among Female *BRCA1/2* Carriers: Facilitators and Barriers to Recommended Follow-Up Care

Ann Louise Tezak, MA, MPH[1]; Anne Weidner, MPH[1]; Kate Clouse, PhD, MPH[2]; Debi Cragun, PhD[3]; & Tuya Pal, MD, FACMG[1]

VANDERBILT UNIVERSITY MEDICAL CENTER

Vanderbilt University Medical Center [1], Vanderbilt University [2], & University of South Florida [3]

GeneCARE

BACKGROUND

- Approximately 5-10% of breast cancers are inherited, most commonly due to mutations in *BRCA1* or *BRCA2* (*BRCA*).
- *BRCA* carriers have a 60-70% risk of developing breast cancer, 50% or more risk of developing a second breast cancer, and up to 44% risk of developing ovarian cancer.
- Risks may be reduced by 90% or more (i.e., to below that of the general population) through preventive options such as removal of breast tissue and ovaries.
- National Comprehensive Cancer Network guidelines for cancer risk management (CRM) include:
  1. Breast CRM: annual mammogram and breast MRI with contrast or risk-reducing mastectomy
  2. Ovarian CRM: risk-reducing salpingo-oophorectomy

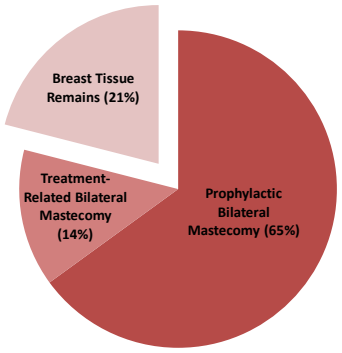
OBJECTIVES

- To examine the uptake of CRM practices among females at-risk for hereditary cancers, in particular those with a *BRCA* mutation, regardless of a cancer diagnosis.
- To expand our understanding of barriers and facilitators to appropriate follow-up cancer care among high-risk women with a *BRCA* mutation.
- To inform follow-up cancer care decision-making patterns and health-seeking behaviors among high-risk women with a *BRCA* mutation.

METHODS

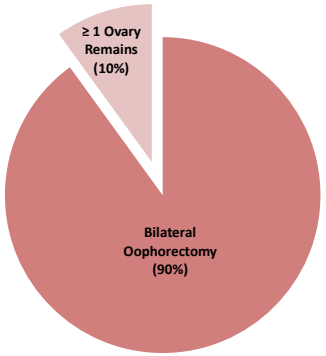
- Demographic/clinical updates and family sharing practices were collected from 186 *BRCA* carriers (regardless of a cancer diagnosis) recruited from prior Vanderbilt studies.
- A sub-group of 24 *BRCA* carriers were purposively selected for in-depth phone interviews based on CRM strategies, family sharing practices, and self-identifying as African American and Hispanic/Latina.

RESULTS



2 (5%) *BRCA2* carriers not adherent

All *BRCA1* carriers remain adherent



1 (5%) *BRCA2* carrier age 49 not adherent

4 (21%) *BRCA1* carriers ages 36-56 not adherent

Top 3 Most Challenging Issues/Concerns (*reported in surveys*)

Scared or not ready to have a mastectomy
Insurance coverage issues
Scared of finding a cancer diagnosis

INTERVIEW THEMES

Decision-Making Patterns

Fear of Surgical Procedures/Recovery: "…I stop and think about I know other people who have gone through that and they have had **so many complications** behind it…so there again too I **don't want to put my family through all of this again** because my baby sister…she was diagnosed in 2003; she did the mastectomy and as far as reconstructive, she was doing the trans flap and she passed away about 2 days after the surgery."

▪ *BRCA1*+ age 60 breast cancer at 45

Barriers to Care

Financial Burden/Insurance Issues: "I wasn't in my job for a long time where I felt comfortable taking off a lot of time, and then **financially I didn't think I could pay** the other 20% the insurance didn't cover…I remembered the surgery, I remember it was painful, and I remember being out of work a lot…**I thought I cant go through that at this time of my life**…That's why I didn't do it."

▪ BRCA2+ age 60 breast cancer at 36

Difficulty Establishing Care: "…**it can be hard to establish care**…it's kind of hard to maybe find the right place, especially because a lot of providers or offices might not really even know that this is a thing, so when I'm calling around, people are a little confused or don't know where to direct me...**staff don't realize that people might need to be seen even if they don't have cancer**."

▪ BRCA2+ age 29 no cancer

Facilitators for Care

Empowering Patients: "Well, I didn't make it that day, but yeah. They did give me plenty of information…**they didn't push me one way or the other.**"

▪ *BRCA2*+ age 63 no cancer

Support System: "I had a **very good support system**, not only my family but close friends…whether it is just your clergy…I had my coworkers you know things of that nature."

▪ *BRCA1*+ age 60 breast cancer at 45

Perceived Susceptibility: "I had to have a mastectomy on the right side, and then when he asked me about the left, I said, "**I'm *BRCA2* positive. Isn't that a no-brainer**?" You know, so I just went ahead and did the other too."

▪ *BRCA2*+ age 64 breast cancer at 39

Perceived Severity: "I would definitely do it again because I understand what ovarian cancer [is]; **how serious that is and how hard it is to catch until it's at the end**."

▪ *BRCA2*+ age 38 breast cancer at 29

DISCUSSION/CONCLUSION

- High rates of adherence to breast and ovarian CRM.
- Breast CRM decision-making patterns were often guided by fear of surgical procedures (i.e., mastectomies and reconstruction) and difficult recovery.
- Common barriers were insurance issues/financial burden and difficulty establishing care as a *BRCA* carrier.
- Facilitators included strong support systems (i.e., family, friends, and providers), healthcare providers empowering patients/supporting autonomy, and perceived susceptibility to/severity of cancer (namely ovarian cancer).
- Next steps include ongoing interviews, analysis, and intervention development.

REFERENCES

Miki et al. 1994, PMID 7545954; Wooster et al. 1996 PMID 8524414; Antoniou et al. 2003 PMID 12677558; Litton et al. 2012 PMID 21913181; Chen et al. 2007 PMID 17416853; King et al. 2003 PMID 14576434; Graeser et al. 2009 PMID 19858402; Malone et al. 2010 PMID 20368571; Domchek et al. 2010 PMID 20810374; Finch et al. 2014 PMID 24567435; Genetic/Familial High-risk Assessment: Breast and Ovarian. Available from UR, accessed April 19, 2019L: http://www.nccn.org/professionals/physician_gls/pdf/genetics_screening.pdf