Self Advocacy as a Member of an Underserved Population

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No disclosures
The reality of genetic testing

- Of the first 10,000 patients tested for BRCA, only 10% reported non-White ancestry\(^1\)
- White women with family history of breast or ovarian cancer are 5 times more likely to undergo genetic testing than Black women with similar family histories\(^2\)
- 91% of genetic counselors are White and only 6% speak a language other than English\(^1\)
- Uptake of risk reduction strategies once testing has been done is lower in minority populations\(^3\)
- The models used to estimate risk may be inaccurate in non-White populations\(^3\)
Criteria for genetic risk evaluation

- Known mutation within the family
- Anyone diagnosed with: ovarian cancer, pancreatic cancer, breast or prostate cancer and of Ashkenazi Jewish heritage
- Diagnosed with breast cancer and under the age of 50
- Diagnosed with triple negative breast cancer and under the age of 60
- Two different breast cancers
- Diagnosed with breast cancer and a close relative (1st, 2nd or 3rd degree) with the above mentioned cancers
- Diagnosed with breast cancer and 2 close blood relatives with cancer
Barriers to widespread implementation

- Patient awareness
- Time needed for appointments
- Cost/insurance
- Distance
- Medical mistrust
- Provider knowledge
- Language barriers
- Limitations in the risk models
- Limitations in acceptable management
Overcoming barriers

- **Patient awareness**
  - Educational forums
  - Community outreach

- **Access issues**
  - Utilization of navigators
  - Telehealth

- **Provider knowledge**
  - CME offerings
  - Educational conferences

- **Limitations in the risk models**
  - Participation in clinical trials
  - Participation in testing

- **Cultural barriers**
  - Culturally sensitive therapies
  - Utilization of interpreters
How to be your best advocate

1. Be knowledgeable about options for testing and what to do with results
2. Ask about genetic testing and/or risk reduction strategies
3. Second opinion when possible
4. Find a support or advocacy organization
References


2. Armstrong K, et al. Racial differences in the use of BRCA1/2 testing among women with a family history of breast or ovarian cancer. JAMA 2005


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Panel discussion