Alternative Models of Clinical Service Delivery: Impact on Disparities in BRCA Testing

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Hereditary Breast-Ovarian Cancer: Alternative Models of Genomic Service Delivery

• Shortage of providers
• Uneven geographic distribution of providers
  – Urban
  – Academic medical centers
• Access to services
• Sub-optimal referral
• Changing landscape of genomic testing
  – Expanded indications in breast cancer
  – Ovarian cancer patients
  – Metastatic prostate cancer
• Increasing recognition that one size does not fit all
Barriers to Genetic Counseling and Testing

• General Barriers – barriers that are broadly relevant to all populations, but may differentially impact underserved/minority populations:
  – Awareness/knowledge
  – Sub-optimal referral
  – Access to services/practical barriers
  – Socioeconomic barriers
  – Attitudes
  – Mismatch with content/process of traditional genetic counseling delivery

• Population-Specific Barriers – barriers that may be specific to a particular population:
  – Language
  – Cultural
  – Implicit bias
Proactive-Rapid Genetic Counseling in Newly Diagnosed Breast Cancer Patients

- RCT: proactive-rapid counseling vs. usual care
- Barriers targeted: awareness, referral, access, practical
- Sample
  - N = 330 newly diagnosed breast cancer patients
  - Aged 50 and younger
  - 30% racial/ethnic minority

Schwartz et al., *Breast Cancer Research and Treatment*, 2018
Genetic Counseling Participation

% Uptake

Usual Care

Proactive-Rapid

NHW
Racial/Ethnic Minority

P=0.47

P=0.06

Post-Surgery
Pre-Surgery
Genetic Testing Participation

- Usual Care
- Proactive-Rapid

Uptake %

NHW | Racial/Ethnic Minority
---|---
Post-Surgical | Pre-Surgical

P=0.02

P=0.27
Telephone vs. Standard Delivery

- Non-Inferiority Trial: telephone vs. standard delivery
- Barriers targeted: access, practical
- Sample
  - N = 669 high-risk women
  - Self- or physician-referred
  - Four sites: Georgetown; Dana Farber; Mt. Sinai; Univ of VT
  - 14% racial/ethnic minority

3-Month post counseling outcomes

Adjusted mean group difference and 97.5% confidence limit
Noninferiority Range

Note: Scores were adjusted for baseline score on the outcome measure and genetic test result

Schwartz et al., *JCO*, 2014;
Interrante et al., *JNCI: Cancer Spectrum*, 2017
Butrick et al., *Genetics in Medicine*, 2015

**Uptake of Genetic Testing Full Sample**

<table>
<thead>
<tr>
<th></th>
<th>Usual Care</th>
<th>Telephone</th>
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<tbody>
<tr>
<td>NHW OR</td>
<td>0.88 (95% CI = 0.40, 19.4)</td>
<td>0.33 (95% CI = 0.17, 0.62)</td>
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<tr>
<td>Racial/Ethnic Minority OR</td>
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Genetic Testing Among Those Who Completed Genetic Counseling

![Graph showing genetic testing uptake among usual care and telephone counseling]

OR = 2.75 (95% CI = 0.61, 12.5)
OR = 0.41 (95% CI = 0.18, 0.92)

Butrick et al., Genetics in Medicine, 2015
Patient and Counselor Process Measures

![Graph showing Patient Report of Counselor Support and Counselor Report of Session Effectiveness]

Tentative Conclusions

• Proactive identification, referral and enrollment could increase participation
  – EMR solutions; embedded staff; navigators; genetic counseling assistants
• Despite increased rate of counseling following proactive enrollment with enhanced access, persistent differences in counseling and testing participation remain
• Telephone delivery can increase access but significant barriers remain:
  – Referral
  – Awareness
  – Attitudes?
• Content of Counseling/Mismatch
  – Cultural/linguistic tailoring
  – Streamlining
Ongoing Projects

Hurtado de Mendoza/Sheppard: Enhancing at-risk Latina Women’s Use of Genetic Counseling for Hereditary Breast and Ovarian Cancer (R03)
- Community Partners: Nueva Vida and Capital Breast Care Center
- Developed a culturally-tailored narrative video designed to address the following barriers:
  - Language, cultural beliefs, lack of referral, awareness

Hurtado de Mendoza/Graves/Schwartz/Hamilton (KL2): Testing a Culturally Adapted Telephone Genetic Counseling Intervention to Enhance Genetic Risk Assessment in Underserved Latinas at Risk of Hereditary Breast and Ovarian Cancer
- Culturally and linguistically tailored
- Targeting information mismatch
- Developing streamlined and tailored visual aids for use during the session

Hurtado de Mendoza/Sheppard: Testing an Intelligent Tutoring System Intervention to Enhance Genetic Risk Assessment in Underserved Blacks and Latinas at Risk of Hereditary Breast Cancer (R21)
- Streamlined and tailored educational tool based on fuzzy-trace theory
- Pilot RCT
Ongoing Projects

Schwartz: Facilitated Education and Testing in BRCA Positive Families (R01)

- RCT of streamlined electronic genetic counseling in families with a known BRCA mutation
- Tailoring based on race/ethnicity
- Goal: increased identification of mutations in first and second degree relatives of known mutation carriers

Graves/Vadaparampil

- 5-year training program for 250 community health educators, navigators, promotores
- Develop cohort with “referral-level competence” to link high risk Latinas to appropriate genetic services
- 1.5 Day in-person workshop followed by 8 online education sessions