Challenges to Conducting Community Based Genetics Research in Puerto Rican Communities in the U.S. and Puerto Rico

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Breast and Ovarian Cancer Risks

Breast cancer by age 50: Up to 50%
Breast cancer by age 70: Up to 87%
Ovarian cancer by age 70: Up to 44%

Risk of Cancer (%)

- General Population
- BRCA Mutation

References:
- Lancet 1994;343:692-695
- NEJM 1997;336:1401-1408
- AJHG 2003;72:1117-1130
- AJHG 1995;56:265-271
Genetic Determinants of Hereditary Susceptibility to Breast Cancer

- Sporadic: 93% (n=178,480)
- Hereditary: 7% (n=12,494) - TP53, LKB1, PTEN, HNPCC

- BRCA2: 25%
- BRCA1: 35%
- Unknown Genes: 35%
Risk Management Guidelines for Hereditary Breast Ovarian Cancer

• **Surveillance**
  - BSE starting at age 18 (monthly)
  - CBE starting at age 25 (semi annually)
  - Mammogram & breast MRI starting at age 25 (annually)
  - TVU and CA125 testing at age 25 (semiannually)

• **Risk Reducing Surgery**
  - Discuss option of risk reducing mastectomy
  - Recommend risk reducing salpingo oophorectomy between age 35-40 or when child bearing is complete

• **Chemoprevention options**
  - Consider Tamoxifen, Raloxifene, Oral Contraception

NCCN, 2007
## Disparities in Genetic Testing

Table 3. Characteristics of the Myriad Genetic Laboratories* BRCA1/2 Testing Database (n = 10,000)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>No.</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total population size</td>
<td>10,000</td>
<td>100</td>
</tr>
<tr>
<td>Sex, female</td>
<td>9,090</td>
<td>90.9</td>
</tr>
<tr>
<td>Age, years</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Median</td>
<td></td>
<td>49</td>
</tr>
<tr>
<td>Range</td>
<td></td>
<td>6-97</td>
</tr>
<tr>
<td>Race/ethnicity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Western European</td>
<td>4,073</td>
<td>41</td>
</tr>
<tr>
<td>Ashkenazi Jewish</td>
<td>3,022</td>
<td>30</td>
</tr>
<tr>
<td>Central European</td>
<td>1,041</td>
<td>10</td>
</tr>
<tr>
<td>Latin American/Caribbean</td>
<td>229</td>
<td>2.3</td>
</tr>
<tr>
<td>Native American</td>
<td>218</td>
<td>2.2</td>
</tr>
<tr>
<td>African</td>
<td>163</td>
<td>1.6</td>
</tr>
<tr>
<td>Asian</td>
<td>112</td>
<td>1.1</td>
</tr>
<tr>
<td>Near/Middle Eastern</td>
<td>91</td>
<td>0.9</td>
</tr>
<tr>
<td>Deleterious mutation</td>
<td>1,720</td>
<td>17.2</td>
</tr>
</tbody>
</table>

NOTE. Adapted from Frank TS.4
*Salt Lake City, UT.

Olopade & Hall, JCO, 2006
Disparities in Genetic Testing: A Multidisciplinary Approach

- Problem: ↓ levels of awareness/knowledge
  - Solution
  - Educate patients and providers about risk appropriate use of genetic services—health education/public health

- Problem: ↓ access to genetic services
  - Solution
  - Create systems to better identify and refer high risk patients—health services research
  - Provide lower cost genetic services—public policy

- Problem: Cultural barriers/factors
  - Solution
  - Train more providers to be aware of and address these issues—health education
  - Develop psychosocial interventions to address these factors—health behavior
  - Recruit more minority professionals to the field of genetics—health education, public policy

- Problem: ↑ UCV
  - Solutions:
  - Understand the functional significance of UCV—molecular biology
  - Evaluate whether variant is segregating with cancer—epidemiology, clinical genetics
How do you eat an elephant?

One bite at a time!!
Main Study

- RO3 from NHGRI to examine at-risk Hispanic women’s knowledge, attitudes, and intentions for genetic counseling and testing related to HBOC
- Inclusion criteria: Aged 18-65, Personal history of breast or ovarian cancer or Mother/Sister with breast cancer < age 50; Female relative with ovarian cancer (any age)
- Self-report as Puerto Rican, Cuban or Mexican (based on demographics of Tampa)
Specific Aims

• To examine knowledge, attitudes, and behaviors related to cancer genetics among Mexican, Puerto Rican, and Cuban women at increased risk for HBOC. (Step 1: Formative Research)

• To develop a series of culturally relevant messages related to HBOC and genetic counseling and testing specific to Mexican, Puerto Rican, and Cuban American women at increased risk for HBOC and identify appropriate dissemination channels for these messages. (Step 2: Message and Materials Development)
Hispanic Ethnicity: Awareness of Genetic Testing

Wideroff et al., 2003
Methods

• Data Collection
  – In-depth face-to-face qualitative interviews
  – 60-90 minutes

• Interview Guide
  – Developed based on review of existing literature & review by expert panel
  – Contains a semi-structured questionnaire and quantitative instruments

• Data Analysis
  – Hand coding
  – Descriptive statistics
Recruitment: An ongoing challenge

- Original strategy: Recruit from local HCHD clinics (n=60)

- Problems encountered:
  - Women very busy
  - Concerned about other health issues
  - Many young women with small children
Mexican, Cuban or Puerto Rican?

We are looking for women who:

- Are 18-65 years of age
- Have a personal and/or family (mother, sister or daughter) history of:
  - Breast cancer diagnosis prior to age 50 or
  - Ovarian cancer diagnosis at any age

We would like to know your opinion about your family’s history of cancer.

If you complete the study, you will be paid for your time

**IF YOU WOULD LIKE TO PARTICIPATE**
(Spanish OR English speaking)

Please call: (813) 745-6102

Your information will be helpful to us to design future programs for Hispanic women

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Mejicana, Cubana o Puertorriqueña?

Estamos buscando mujeres entre las edades de 18 a 65 que tengan un historial personal y/o familiar (madre, hermana o hija) de:

- Diagnóstico de cáncer de seno antes de los 50 años de edad
- Diagnóstico de cáncer de ovario a cualquier edad

Nos interesa saber su opinión acerca de la historia de cáncer en su familia

Si usted completa el estudio, se le pagará por su tiempo

**SI LE INTERESA PARTICIPAR**
(Qué hablen español o inglés)

Llamar al (813) 745-6102
Su información nos ayudará a diseñar programas para las mujeres Hispánicas en el futuro
Recruitment Sources

- Flyering at local Businesses: 52
- Press releases/Newspaper ads: 17
- DOH: 11
- Events/Health fairs: 11
- Moffitt website/newsletter: 10
- LCS: 3

Total: 96
Moffitt investigators conduct genetic awareness study among Hispanic women

If you are a Hispanic woman and you or one of your family members has had breast or ovarian cancer, Moffitt Cancer Center wants to hear from you. Researchers want to talk to women about how much they know about cancer genetics and how they get their information. The study will focus on Hispanic women because they are typically diagnosed with cancer later than women of other ethnicities and they’re more likely to die of the disease.

“A lot of women don’t know their family history. Cancer isn’t talked about in some families, particularly Hispanic ones,” says Gwendolyn Quinn, Ph.D., a member of Moffitt’s Health Outcomes & Behavior Program.

Dr. Quinn and Susan Vadaparampil, Ph.D., M.P.H., received a two-year $100,000 grant from the National Human Genome Research Institute. The researchers want to interview women who themselves or whose mother or sister developed breast cancer before age 50 or had ovarian cancer at any age. They’re targeting Mexican, Cuban, and Puerto Rican women between the ages of 18 and 65.

One of the goals of the study is to develop health information that is culturally and linguistically appropriate. “Often, Hispanic women refer to a family history of cancer as ‘running in the blood.’ There is no real term that translates ‘genetic predisposition’ into Spanish,” says Dr. Quinn.

Also, some cultures adopt a fatalistic approach to cancer, implying that their health outcomes are beyond their control.
Recruitment Source of Participants On-Study (n=32)

- DOH: 1
- Flyer Tampa area: 5
- Flyer Wimauma area: 5
- Flyer Brandon area: 4
- Moffitt website/newsletter: 4
- Bay News 9/Newspaper ads: 7
- LCS: 2
Ineligibility Challenges

- High willingness in PR populations, low in Cuban and Mexican
- Already had genetic testing (not including prenatal)
- Telling friends about the study
- Not knowing exact cancer diagnosis (e.g., “a female cancer”)
- Telephone screening vs interview
Reasons for Ineligibility (n=70)

- Other Hispanic: 18
- No breast/ovarian cancer hx: 20
- Unknown cancer site: 6
- Age of BC diagnosis: 11
- Cancer genetic testing done: 5
- Not FDR: 10
Lessons Learned

• Study Materials
  – Medical translation not always meaningful to participants
  – The shorter the better
  – Expert panel a cost effective method of reviewing materials

• Recruitment
  – Flyering local businesses and press releases an effective recruitment method
  – Approach women at a time when they are not occupied with other concerns
  – Face to face approach more effective in getting flyers posted
  – GPS good system for identifying Hispanic businesses
  – Family history not always readily available/known

• Interviewing
  – Public libraries a good place to conduct interviews
Acknowledgements

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