Risk Assessment, Navigation and Community Perspective: Data and Experience

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Assessing Risk of Breast Cancer through Outreach to Latinas with Education and Support

Risk Assessment: Identification of Individuals for Cancer Genetics Risk

REVIEW OF FACTS

- Latinas have the second highest prevalence of *BRCA1/2* mutations following women of Ashkenazi Jewish ancestry
- Despite priorities to increase racial and ethnic diversity of patients who participate in genetic counseling and risk assessment, striking disparities remain
- Compared to non-Hispanic Whites, Latinos have lower awareness of hereditary risk, lower breast cancer genetics knowledge; lower health literacy and numeracy, and lower testing uptake
- In our experience at Nueva Vida (and in the literature), Latinas report **positive attitudes and interest** in participating in genetic counseling and risk assessment

Navigation & Community Perspective: Latinos in the National Capital Region

Hispanic or Latino : 14.1%

- **Top Three Latino Origin Groups:**
  - Salvadoran **32.4%**
    Mexican **16.3%**
    Guatemalan **7.6%**

Navigation & Community Perspective: Latinas at Nueva Vida

Overall cancer prevalence by Latino subgroups and ages at Nueva Vida

- Central America 43%
- South America 39%
- Mexico 10%
- The Caribbean 8%

- **El Salvador 27%**
- Perú 13%
- **Mexico 10%**
- Bolivia 9%
- Colombia 7%
- **Guatemala 5%**
- Honduras 5%
- Dominican Republic 4%
- Nicaragua 4%

Ages

-**Less than 40 years of age:** 10%

-**Ages 40-49 years:** 16%

-Ages 50-64 years: **49%**

-Ages 65-74 years: **17%**

-Ages 75 years or greater: **8%**

Navigation & Community Perspective: Nueva Vida's Strengths and Experiences

- **Knowledge of the Latino Community and Culture**
  - Deep understanding of values, culture, habits, complexity of immigration issues, demographic locations and characteristics of the population
- **Trust and Credibility**
  - Relationships are essential for stablishing credibility
  - Be a leader and advocate within and for your community
  - Actions speak louder than words
- **Strong partnership with local and national institutions, clinics, hospitals, community-engaged research centers (CEnR)**
- **Partnership to explore telegenetics**
  - George Washington University
  - Provide videoconference sessions for pre- and post-test genetic counseling
  - Provide interpretation for English Speaking genetic counselor

Facilitators identified by Providers and at-risk Latinas

- Main Facilitators for genetic counseling: Family, inform treatment/prevention, respect

"You get people who come here and go "I'm here because my doctor told me I had to, but I don't know" (Genetic counselor)

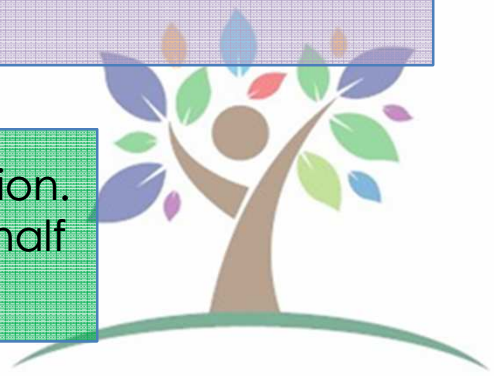
"It would be motivating to do this to help the rest of my family" (at-risk Latina)

Barriers identified by Providers and at-risk Latinas

- Main Barriers: Access, awareness, language, health literacy, misconceptions, negative emotions, lack of referrals

"We have had some (Latina) patients, but with insurance, they have gone through counseling. But without insurance? It is out of the question. There is no mention of it!" (Navigator)

"The problem in this country is the language and the information. In my case, almost everything was in English, so I understood half and had to make up the other half" (Latina survivor)



Knowledge Gaps: At-risk Latinas

- Unaware that age at diagnosis is a risk factor
- Beliefs that access barriers cannot be overcome

- False beliefs / Lack of Awareness:
  - Pap smears screen for ovarian cancer
  - Genetic testing is a cancer diagnostic test
  - The word mutation confused with mutilation, amputation, or metastasis
  - Mutations for HBOC only come from the mother's side

Tips for Explaining Genetic Information to Lay Audiences

- Visual aids (pictographs)
- Natural frequencies vs. percentages
  - 60 women out of 100 (vs. 60%)
- Interpretive labels to convey the meaning of important information
  - High risk
- Less is more: Reduce amount of information
- Highlight key messages: headings, boxes, lists, pictures, visual cues

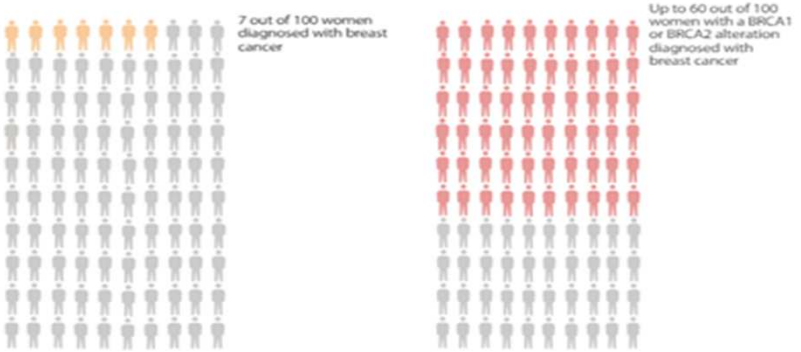
Fischhoff, Baruch. *Communicating risks and benefits: An evidence based user's guide*. Government Printing Office, 2012.

Examples

BRCA ALTERATIONS

A SECOND BREAST CANCER

Chances of developing a second Breast Cancer within 25 years post diagnosis



HIGH !

In general, out of 100 women who have been diagnosed with breast cancer and have a change in the BRCA1 or BRCA2 gene, up to 60 will get a second breast cancer within 25 years after first diagnosis.

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Pictograph

Interpretative Level

Natural Frequencies

Examples: Inheritance and Genes

CANCER IN THE FAMILY

Headings

Boxes

CANCER

- Cancer happens when **cells** in your body grow in an abnormal way.
- Cancer can be caused by different factors, including **hereditary factors**.

Bold

Colors

LET'S TALK ABOUT YOUR FAMILY

Pictures

The information that you will receive today is also important for them!

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GENES

GENES

- Genes are passed down over generations in a family through the mom and dad.
- They are like instructions for our bodies.

We have no control over which genes we receive from our parents or pass on to our children

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