

## Introduction & Purpose

- Breast Cancer (BC) has the 2<sup>nd</sup> highest cancer incidence for women in the US
- BC represents 16% of Latinas' cancer deaths each year
- Latinos constitute only 2% of all biobanking and 1.3% of cancer-related clinical trial participants
- The aim of this study is to better understand Latinas' decisions to participate in cancer-related clinical trial research and how their choices are affected by researcher recruitment methods, the views of family and friends, and by the knowledge of their underrepresentation in medical research

## Latino Health Culture

Health Culture	Definition
Familismo	Loyalty and faithfulness to one's family is more important than one's own needs
Collectivism	A community's goals or needs are more important than one's own needs or goals
Fatalismo	An individuals' diseases or health conditions are pre-determined by destiny or fate
Promotores	Latinos who work in their community to decrease healthcare barriers

## Grounded Theory

- Grounded theory is commonly applied when researchers should consider context and time or when there is a lack of information surrounding the question
- Grounded theory allows researchers to create a framework based on the analysis of qualitative data
- Interviews are continually coded and common themes are determined from the interviews
- At the conclusion of the coding and data collection, researchers develop theoretical ideas based on the themes

## Methods

- Twenty Latinas who had previously donated their healthy breast tissue to the KTB participated in one-on-one, in-depth interviews guided by **grounded theory** to investigate their motivations to donate their tissue to the KTB.
- Interview transcripts were coded and grouped thematically.

## Findings & Discussion

### Bilingual Researchers and Research Materials

"We were able to build a bilingual program...when we met them where they were, we had a lot more turn out."

"Hispanic people usually go to Spanish-speaking doctors...because they feel more connected to them."

**Rather than researchers studying Latinas' barriers for clinical trial participation, researchers must take responsibility and do a better job of recruiting Latinas into their clinical trials.**

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<sup>3</sup>Susan G. Komen Tissue Bank at the IU Simon Comprehensive Cancer Center, Indianapolis, IN

## Researchers Call to Change:

- Latino researchers should be involved in clinical trial research and recruitment
- Use research materials that are translated by someone with Spanish as a first language (Byrne et al., 2020)

## The Legacy Norm

"Just knowing that they're going to be helping...possibly themselves, their moms, their families."

"Remind them that they have this opportunity to hold their, that population, their population"

"To improve the lives of the people around me. Whether it's in my community, whether it's in my family, whether it's people like me"

- The legacy norm construct centers around altruism, care for others, self-sacrifice, and awareness of the future for people like oneself
- Latinas' responses demonstrated the legacy norm—with the hope that their participation would specifically help Latinas both now and in the future

## Researchers Call to Change:

- Research materials that state the under-representation of minoritized populations in clinical trial research
- Research materials should emphasize how participating in research improves the present and future health of others like them

## Against Cultural Norms

"My husband didn't like that idea... It was a little bit of machismo."

"I did ask my mom....to try to get her to go with me...She was just horrified, like why would I even ask her?"

## Researchers Call to Change:

- Family support for clinical trial participation may not be an influential factor in decision making as seen in other health-related decisions
- Emphasize their individual choice to participate in research

## Limitations

- This study was relatively small (N=20)
- Country of origin was not asked by participants of the study, so results could not be analyzed to see if viewpoints varied based upon country of origin