

LDI SUMR Symposium

Health Needs Assessment of Hispanic Women with Breast Cancer in Philadelphia

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Background

20%

0%

Self-Reported

Fair or Poor Health

HISPANIC/LATINO HEALTH MEASURES



Insured

Poverty

21.6%

Smoking

Obesity

13.8%

15.6%

Diabetes

Asthma

Mental

Health Condition

Specific Aims

- 1. To identify and better understand the needs of Hispanic women with a diagnosis of breast cancer.
- 2. To identify and better understand the needs of the caregivers and health care providers of this population.
- 3. Use this study to inform design of intervention(s) to help meet the needs of this growing population.

Mixed-Methods Design

- Qualitative
 - Semi-structured interviews with Hispanic patients with breast cancer, caregivers and providers of this population in English and Spanish
 - By interviewing the 3 different groups, achieve triangulation
- Quantitative
 - Demographics
 - Supportive Needs Care Survey
 - Both questionnaires created in REDCap
- ► Informed consent obtain by reading a statement of research prior to virtual or phone interviews
- ► IRB application submitted and approved on 8/3/21

Semi-structured interviews

Current challenges

- As you think of your Hispanic patients, and drawing from your experiences, what are the current challenges that must be addressed to increase access to time-sensitive cancer care?
- What are some potential strategies to overcome these challenges?
- What would be some of the barriers to implementing these strategies?

Existing resources

 What existing support systems can Hispanic patients with cancer access at your cancer center or in the larger community that you might know about? Are there any others?

Patient communication

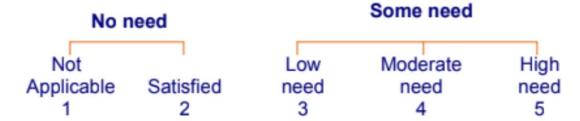
 When patients learn about their treatment options, are they typically asking to learn about other treatments such as cancer clinical trials?

Model patient

What is something that Hispanic patients should know when seeking care, but might not?

Supportive Care Needs Survey (SCNS-LF59)

► Response scale



► Domains:

- Psychological
- Health system & information
- Physical & daily living
- Patient care & support
- Sexuality

Table 2: Psychological needs items and factor loading

Item	Anxiety about having any treatment
	Fears about physical disability or deterioration
Fears about losing your independence	Accepting changes in your appearance
Confusion about why this has happened to you	Worry that the results of treatment are beyond your control
Feeling bored and/or useless	Uncertainty about the future
Anxiety	Learning to feel in control of your situation
•	Making the most of your time
Feeling down or depressed	Keeping a positive outlook
Feelings of sadness	Finding meaning in this experience
Fears about the cancer spreading	Feelings about death and dying
Fears about the cancer returning	Concerns about the worries of those close to you
Fears about pain	Changes to usual routine and lifestyle
•	Concerns about the ability of those close to you to cope

Recruitment of Participants

- Snowball sampling
- ► Breast Cancer Support Group for Hispanic Women with Breast Cancer
 - Morivivi founder Marla Vega
- ► Penn Medicine Breast and Cervical Cancer Early Detection Program
 - A CDC and PA DOH funded program that offers free mammography to women who are un/underinsured (Guerra is PI)
 - Penn Medicine BCCEDP navigator, Emily Verderame
- Penn Medicine Breast Cancer Providers
 - Surgical, Medical and Rad oncology providers (physicians, nurses, NPs)
 - Dr. Alina Mateo, Assistant Professor of Surgery
 - Dr. Sandra Adaniya, Assistant Professor of Medicine
- ► Estimated sample size ~30 or until thematic saturation is reached

Analysis

- All interviews recorded and transcribed
- NVivo qualitative data software used for analysis and coding of the interviews
- Analyzed for themes using Grounded-theory
 - Grounded theory: a paradigm designed to generate theory; the idea that theory should be 'grounded' in data (positivistic)
 - Influential concepts: theoretical saturation, open coding, constant comparative method (coding as we go)
 - What's it good for? Research areas in which little theory is available; generate new theory (as opposed to presenting data), and reduce big data sets
 - Challenges? Can be overly formal; positivistic.

Preliminary Results – Barriers to care

Patient perspective

- Cultural → "I know Latina Hispanic woman are very prone to just taking care of the family, so they may you know put off their health because they take their family as a priority, so it's a barrier and that's in their culture."
- Education → "In my opinion, they do not participate in the sessions related to their treatment they just sit down and listen to what the doctor needs to say. They do not ask any questions, they just receive. Then, when you ask, some of them don't even know how to explain to you"
- Communication → "When a patient is going to have a diagnosis, they should have someone in their language to explain to them, I know that many hospitals have a translation service, but it's not face to face. We as Latinos need someone to hold hands or just a shoulder."

Preliminary Results – Barriers to care

Provider perspective

- Cultural Hindrance → "We don't talk about cancer, we don't go for screening, we don't really do that. So when my sister has cancer, we don't really talk about that."
- Education → "There's not a lot of Spanish literature; a lot of times I'm doing the education in the clinic. All of this takes time and we only see patients for 45 minutes."

Preliminary Results – Facilitators to care

Patient perspective

- **Accompaniment** → "Provide interpretation services they need, accompany them so they know where to go, and empower them at some point to be able to go by themselves."
- Community Patient Navigator → "Someone that is part of the community, knows the people, and the people will trust because this is from their own neighborhood. Then there's the patient navigator who has more knowledge about signs. That's a big difference, but if we all work together we could go to the field, look for clients that need help and bring them to the patient navigator at their hospital."

Preliminary Results – Facilitators to care

Provider perspective

- Navigators → "I'm a patient navigator... I enroll [un and underinsured] women who need
 mammograms and other breast services and then also decrease any barriers they may
 have, such as language, culture, transportation... If they're diagnosed with breast cancer,
 then I'll enroll them for health insurance to be treated at the cancer center."
- Representation → "Physicians that look like them, speak like them, and connect with them.
 They know what their barriers are whether it could be as simple as 'I don't have a car,' and sometimes they don't volunteer that information."
- Cost-Free Programming → "We call it the Healthy Women's Program where they can come in and receive free mammograms so all women and men that have no insurance are guaranteed yearly screening mammograms. If needed, we schedule a biopsy, and if we diagnose cancer, then they go to our clinic and we get them emergency insurance so we can cover their surgery."

Conclusions

- ► The needs of Hispanic patients with cancer do not appear to be fully met
 - Education, timely care, financial, communication/language needs are going unmet
- ► Intervention should result in empowerment of patients and caregivers to seek resources that will meet the needs of this population
 - Ex. patients should not be afraid to seek a second opinion.
- Dedicated and diverse workforce may be needed to meet the needs of this population
 - Diverse navigators, physicians, nurses
 - "You can spend an entire half day just dealing with one patient when we have multiple patients so really it's staffing from our standpoint."

Lessons learned

- Write a protocol, IRB application and submit for approval
- Learn and understand the needs of the Hispanic population in Philadelphia and the role of caregivers for this population
- ► Use qualitative and quantitative data to begin to think about what solutions look like to providers, patients, and caregivers.

Future Directions

- ► Recruitment through support groups and various medical providers.
- Analysis of qualitative and quantitative data to more comprehensively identify salient themes
- Member checking to increase validity of the results and rigor of the science

NVivo codebook inter-rater reliability

Thank You!

► Dr. Guerra, Joanne, LDI, SUMR Scholars, my parents