

Latina Breast Cancer Survivors: Our Experiences

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Background

- Collaboration with Partnered for Progress and the Latina Task Force
- Questions of interest to the community
- Literature review
 - Little work has characterized Latina breast cancer survivors' experiences with medical care

Pilot Project Aims

To improve our understanding of Latina breast cancer survivors'

- Views on their access to and quality of care
- Problems and sources of support
- Meaning of being a breast cancer survivor

Why a CBPR Approach?

- Increased community motivation to participate in research process
- Increased acceptability of study approach
- Enhanced recruitment and retention
- Increased reliability and validity of measures
- Increased potential to translate findings into effective actions/ interventions
- Increased community capacity to take action

Establishing a Community-Academic Partnership

- Community and academics as partners in research
 - development of study questions, aims, approaches
 - analysis and interpretation
 - dissemination of findings to all partners, community and academic

Focus Group Methods

- Inclusion: Latinas between 6 months and 10 years post-breast cancer diagnosis
- Recruitment: Health events, *Promotoras*, PFP newsletter, flyers at hospitals, support groups
- Question development: Iterative process involving all partners
- Data collection: Semi-structured focus group discussions

Qualitative Data Analysis Methods

- Review transcripts by academic and community partners
- Mechanical: organize and code text into analytic categories
- Interpretive: Content analysis to discern meaningful patterns and draw conclusions
- Iterative process including all partners

Participants

74 Women, 12 Focus Groups: 6 English, 6 Spanish

Age: 30-75 years (50 average)

Stage: 2/3 early, 1/6 late, 1/6 didn't know

Language: 60% Spanish

Generation in US: 60% 1st

Health Insurance: 1/2 private, 1/2 public

Information Needs, Shared Decision-Making, Choices

Patients report receiving information, plans; satisfied with degree of shared decision-making

OR

Patients don't receive enough information, don't understand what to expect; dissatisfied with degree of shared decision-making

→Confusion, uncertainty over quality of care

Information Needs, Shared Decision-Making, Choices

Common hunger for information on:

- “Right” schedule for follow-up visits, mammograms, blood tests
- Impact of radiation from follow-up mammograms
- Nutrition, CAM, other self-care

Role of Health Insurance

Health Insurance Coverage

- MediCal/County → poor continuity
- Loss of insurance due to inability to work or time limited MediCal → disrupted hormonal therapies, provider continuity
 - “The doctor told me to continue the pills for 5 years. But they took away my MediCal, so I missed a year’s treatment.”

Medical Care, Other

Other Common Issues

- Lack of time with doctor, lack of caring
 - “My PCP doesn’t seem very understanding about breast cancer. Its like, ‘You’re done -- Next!’ ”
- Lack of coordination among physicians
- Few reports of patient navigation
- No reports of formal survivorship plans
- Little mention of language access

Challenges and Sources of Support

Challenges

- Physical functioning
- Emotional/Role functioning

Sources of Support

- Spirituality/Faith
- Family
- Faith community
- Support groups
- Activation/Self-empowerment

Challenges and Sources of Support

On Support Groups

- “I found it culturally insensitive. They said that you should be able to “flash.” Maybe women in the dominant culture feel comfortable doing that, but I never heard of a Latina getting together with her sisters and saying, ‘Here, wanna see my scar?!’”

On Self-Empowerment

- “I come from a background where, whatever the doctor says is the last word, whatever your husband says is the last word, whatever the priest says...so it was really hard for me to find that strength to empower myself.”

Meaning of Being a Survivor

Negative

- Stigmatizing, victimizing
- Holding onto the past
 - “It’s like having PTSD: I don’t like identifying as a survivor because I don’t like thinking about the cancer at all, giving it any power.”
 - “ I see the word survivor as a negative because I think it is a constant reminder of what we’ve gone through, as opposed to looking towards the future. It also just brings me down in terms of being a victim. I’m not a victim.”

Meaning of Being a Survivor

Positive

- Strength, “we are fighters”
- Grace, blessing, new opportunity, to enjoy life, to help others
 - “In the end, we are warriors.”
 - “You should feel like a woman who fought for her life, and if you didn’t do it for yourself, your children gave you the strength to go on, and your husband, and obviously God. All women who have gone through this are to be admired, and God has chosen them for something.”

Latina Survivor Recommendations

- To patients/survivors: ask questions!!!
- To policy makers:
 - More research on breast cancer causes
 - More research on their daughters' risk
 - More education of Latinas, especially young women, on prevention and early detection
 - Greater access to screening services
 - Education and support groups for family members and caregivers of survivors

Potential Future Studies

- Development and evaluation of culturally appropriate support intervention for survivors, family members, caregivers
- Development and evaluation of provider training to improve provider-patient communication
- Exploration of the role of spirituality, faith, and faith communities in supporting survivors

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Latinas: Salud y Vida