Post-mastectomy breast reconstruction experiences of Spanish-prefering Latinas

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Includes similar qualitative studies of breast reconstruction utilization among African American and lesbian women

Lisa R. Rubin, Principal Investigator
The Women’s Health and Cancer Rights Act of 1998

- Health plans that cover mastectomies must also cover:
  - Reconstruction of affected breast
  - Surgery on unaffected breast “to produce a symmetrical appearance”
“Use of Breast Reconstruction After Mastectomy Following the WHCRA”
Assessed breast reconstruction rates following the implementation of the WHCRA in 1999 using SEER data in multiple sites

Results
- Ethnic/racial minority women still significantly less likely to receive post-mastectomy breast reconstruction

Conclusions
- “Factors other than health insurance coverage are driving practice patterns in breast reconstruction.”
Katz, et al. (2005)

“Breast Cancer Treatment Experiences of Latinas in Los Angeles County”

Combined SEER and questionnaire data

Compared non-Latina White, African American, and Spanish and English-preferring Latinas

Results

- Spanish-preferring Latinas least likely to receive breast reconstruction and least satisfied with surgical decision-making process
The current study

- A qualitative approach
- Seeking to uncover processes that lead to differential utilization of breast reconstruction across ethnic/racial groups
- Investigate linguistic and communication issues that Spanish-preferring Latinas encounter
Inclusion criteria

- Self-identified as Latina
- Received a mastectomy since the implementation of the WHCRA
- Chose to conduct interview in Spanish
Data collection

- Three recruitment centers
  - Center A: Community-based cancer treatment and support center serving medically underserved populations
  - Center B: Community-based cancer support center serving Latinas
  - Center C: Private cancer treatment and research center

- Semi-structured interviews conducted by Spanish-speaking Latina interviewer
Sample characteristics

- **N = 11**
  - 6 no reconstruction
  - 5 reconstruction (3 implant, 2 TRAM/autologous)

- **Mean age = 55.5 years (43-73)**
  - No reconstruction = 57.7 (43-73)
  - Reconstruction = 55.1 (44-71)

- **Country of origin**
  - 4 (36%) Puerto Rican
  - 2 (18%) Columbian
  - 2 (18%) Dominican
  - 1 (9%) Cuban
  - 2 (18%) unknown
Grounded Theory (Glaser & Strauss, 1967)

- Research inspired by and “grounded in” general problem or phenomenon
- Data analysis and interpretation are “grounded in” the data, rather than a priori theory
- Can be interpreted as a general epistemological approach to qualitative research rather than a “unitary method” (Henwood & Pidgeon, 2003)
Data Analysis

- Open coding of interview content
- Iterative approach adapted from Huberman and Miles (2005): A “dialog between ideas and evidence”
  - Data reduction
    - Subset of participants (Spanish-preferring, based on Katz et al.)
    - By code
  - Data display
    - Scatterplots
    - Ordered meta-matrices
  - Conclusion drawing/verification
    - Memo writing
    - Creating categories and themes
    - Contrast and compare cases and groups
## Data display: Scatterplot

<table>
<thead>
<tr>
<th>Insurance</th>
<th>Community-based treatment and support center</th>
<th>Community-based support center</th>
<th>Private treatment center</th>
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<td><img src="Image7" alt="R07" /> <img src="Image8" alt="R09" /> <img src="Image9" alt="R06" /></td>
<td><img src="Image10" alt="R10" /> <img src="Image11" alt="R11" /></td>
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- ![Implants](Image12)
- TRAM/Autologous tissue reconstruction
- No reconstruction
Selected Preliminary Results
Preliminary results: Reasons for choosing reconstruction

- To cover evidence and memory of cancer (for self and others)
- Completeness, not to have something “missing”
- Femininity, to feel “like a woman”
- For partner, encouraged by partner
- Advice and encouragement from physicians
Preliminary results: Reasons for not receiving reconstruction

- Major reasons cited:
  - Age (feel too old)
  - Partner status (no partner)
  - Age/partner
    - “If I’ve been alone for so many years, at my age, I’m 73 years old, why would I look for someone now?”
  - Additional procedures (pain, complications)
  - Not seen as necessary
  - Support systems (support group, family)

- Missed work/income, failure to qualify for health reasons, and not being offered reconstruction were not major reasons cited in this group
Preliminary results: Language in treatment context

• Language or interpretation issues not cited as primary barrier to relationship between the patient and the treatment team:
  ○ Quote from participant N06, a 73 year-old woman of Columbian origin who had been living in the United States for 24 years:
    ● “Well, it doesn’t matter. If I talk to the doctor, I speak in Spanish. Well, it’s better if they speak Spanish because we don’t need to have an interpreter, but I feel good either way.”
Preliminary results: Personalismo and simpatía

- *Personalismo* - patients may discuss non-medical issues in visit or ask physicians about their personal lives (Pérez-Stable & Nápoles-Springer, 2001)

- *Simpatia* - keeping interpersonal relationships free of conflict and unpleasantness (López & Katz, 2002)
Quote from participant N05, 43 year-old woman of Dominican origin describing what makes a good physician and what can be done to make patients feel more comfortable:

“\textit{Oh, they talk to you. They act like they’re already your family. The conversation, the way they treat you. They are very friendly and sweet with you.}”
Preliminary results: Personalismo and simpatía (cont.)

- Lack of *personalismo* and/or *simpatía* can lead to loss of *confianza*, or confidence in physician.
- Quote from participant N01, a 66-year old woman who was told she was “too fat” for reconstruction at first:
  - “I didn’t like his attitude, because if you are going through a tragedy as breast cancer and here comes this doctor to tell you so many things--I decided not to--if this doctor is like this, and the others are like this, I will not have breast surgery.”
Preliminary results: Familismo

- *Familismo* - identification with one’s family; sense of duty or loyalty to family (Triandis et al., 1982; López & Katz, 2002)

- Understanding of familismo and the immigration experience’s influence on familismo is still a barrier, even if the linguistic barrier is overcome
Quote from participant N03, a 57 year-old woman of Puerto Rican origin who had been living in the United States for 24 years describing an encounter with a physician:

“So then, when we get to the office and we go in, she explains all that to me and I ask for her opinion, then I ask her if my cousin can come in so that she can explain to him--she asks me, ‘What for?,’ and I tell her, ‘What do you mean what for, doctor? I don’t have any family members here. I don’t have anyone here.’”
Discussion: What these data tell us

- Looking at the experiences of Spanish-preferring Latinas through a qualitative lens can tell a different story.
- Culture may be underlying observed differences in quantitative studies.
Discussion: Limitations

- Intersectionality limits potential for theoretical saturation
  - Experiences and identities influenced by other factors
  - Latina as a multi-dimensional construct

- Applicability of findings to general Latina population
  - Sample largely of Caribbean origin
  - Limited to New York
Discussion: Future directions

- Analyze data by cancer treatment and reconstruction stage (e.g. diagnosis, mastectomy, reconstruction referral, reconstruction consultation, etc.)
- Comparison with English-preferring Latinas
- Theoretical sampling
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