Surgery and Invasive Lobular Carcinoma: A Patient Experience Survey from the Lobular Breast Cancer Alliance

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What we learned: Survey results support the need for improved pre-operative staging and imaging modalities specific to ILC.

Background

- The Lobular Breast Cancer Alliance (LBCA) is a nonprofit, patient advocacy organization committed to raising awareness and promoting research into invasive lobular carcinoma (ILC).
- ILC accounts for **15%** of breast cancers, but knowledge about ILC remains limited.
- ILC's hallmark is lack of E-cadherin, which results in non-cohesive formation. This impacts how effectively imaging methods can detect and stage ILC tumors.
- Consequently, patients with ILC have higher rates of positive surgical margins, mastectomies, and axillary lymph node (LN) dissections.[1]

1. Piper ML, et al. Success rates of re-excision after positive margins for invasive lobular carcinoma of the breast. NPJ Breast Cancer. 2019 Sep 6;5:29. PMID: 31508489.

Objective

To understand the surgery and surgical decision-making experience of individuals with ILC. Issues examined included:

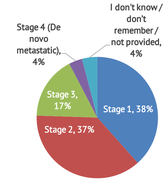
- Pre-operative imaging
- Types and numbers of surgeries
- Decision making and patient experience with surgery
- Surgical margins
- Lymph node status

Methods and Cohort

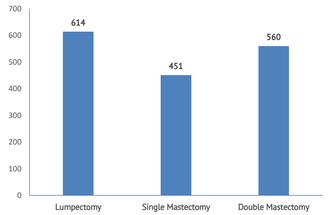
- Anonymous online survey conducted 6/21/23 to 7/2/23
- Survey respondents recruited via the LBCA newsletter, social media, and partner organizations
- **1,482** individual respondents; analyses were limited to **1,426** who had undergone surgery
- Average age of respondent at diagnosis was 56 (range 31-86)
- **75%** of respondents indicated they had dense breasts

Results

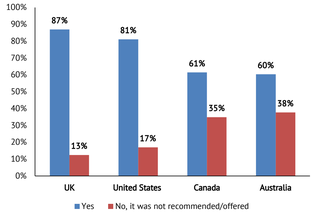
Clinical Stage at Diagnosis



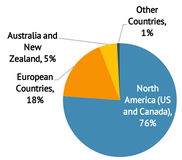
Number of Surgeries Reported



Respondent MRI Utilization by Region



Survey Respondents By Country



Respondents Share Their Reasons for Surgical Decision Making

Of the 560 respondents who had a **double mastectomy (DM),** reasons given included:

- **60%** thought it would improve overall survival
- **50%** worried about potential for local recurrence in remaining breast tissue if they did not have DM
- **47%** had concern that imaging wouldn't detect ILC tumors in the future
- **45%** had concern that ILC is more likely to be bilateral
- **42%** said they agreed with care team recommendation

Of the 451 respondents who had a **single mastectomy,** reasons given included:

- **75%** said they agreed with care team recommendation
- **35%** thought it would improve overall survival
- **20%** worried about the potential for local recurrence
- **15%** had concern that imaging wouldn't detect ILC tumors in the future

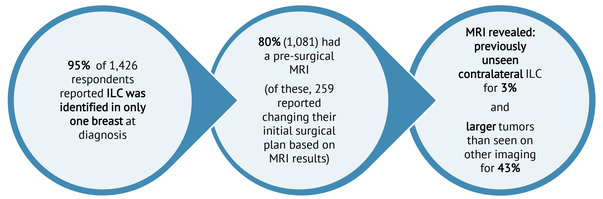
Of the 614 respondents who had a **lumpectomy,** reasons given included:

- **83%** said they agreed with care team recommendation
- **25%** wanted to keep their breast
- **14%** thought it would improve overall survival
- **13%** indicated they wanted breasts and did not want reconstruction

Respondents Reported Challenges Attaining Clear Margins Regardless of Surgery:

- Of 614 respondents who had a *lumpectomy*, **33%** had positive margins at first surgery.
  - Of the **33%**, **17%** reported multiple lumpectomies and a subsequent mastectomy; **24%** reported clear margins were *never* achieved.
- Of the 1,011 *single and double mastectomies* reported, **10%** did not achieve clear margins after these surgeries.

Pre-Surgical Imaging Remains a Challenge



In 375 instances **(26%)**, survey respondents diagnosed with ILC in one breast who had had a pre-surgical MRI, reported the MRI *did not reveal new information* about their ILC. Of these, **post-surgical pathology revealed that invasive breast cancer had been undetected by the MRI:**

- **16%** had additional ipsilateral foci (more cancer in the single breast)
- **2%** had contralateral disease (cancer in the other breast)
- **40%** had larger tumors than seen on pre-surgical imaging

Post-surgical pathology for those who had a double mastectomy revealed larger tumors than seen on imaging (57%), and 6% had tumors found in a second breast that were not seen on imaging.

Discussion and Limitations

- This survey demonstrates the experience of a large cohort of women with ILC, reporting high rates of uncertainty about the accuracy of imaging, high rates of repeat surgery, bilateral mastectomies, and positive margins.
- Patients may have varying degrees of understanding of how surgical choice relates to survival. It is further noted that concerns about how well and whether ILC is detected affect surgical choices.
- Patients are factoring concerns about potential extent of disease and future recurrence in their surgical decision making.
- Study limitations include potential recall and selection bias.

Next Steps / Acknowledgements

- Authors hope results inspire more ILC research to improve imaging.
- LBCA is committed to sharing the newest information about ILC and surgery with the lobular breast cancer community.
- LBCA thanks respondents for sharing their time and experiences in this survey.

This poster is dedicated to the memory of LBCA Board Member Dr. Deborah Mueller.

