Invasive Lobular Breast Cancer and Surveillance: A Patient Experience Survey Study

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LBCA Website

WHAT WE LEARNED: Low confidence in surveillance related to high fear of cancer recurrence.

BACKGROUND

- The Lobular Breast Cancer Alliance (LBCA) is a nonprofit, patient advocacy organization dedicated to raising awareness and advancing research on invasive lobular carcinoma (ILC).
- ILC accounts for **15%** of breast cancers and remains understudied.
- Lack of E-cadherin causes ILC to spread in single cells rather than form a lump, making it harder for imaging tests to detect.
- Imaging studies can be less accurate for diagnosis, staging, and detection of recurrence or progression.

OBJECTIVE

Many patients express concern about efficacy of current surveillance protocols used with them to detect returning or progressing disease. This survey study aimed to:

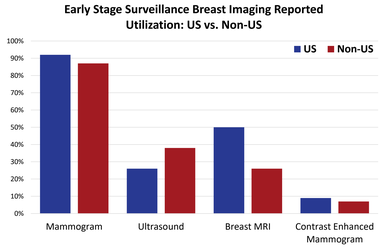
- Understand current surveillance practices used with people who have had early-stage (ES) ILC and/or are living with metastatic ILC (mILC). Note: Surveillance for this survey was understood to generally include some combination of routine imaging, physical exam, and/or bloodwork depending on disease stage and individual.
- Assess patient confidence in their surveillance plans.
- Measure fear of cancer recurrence or progression (FCR).

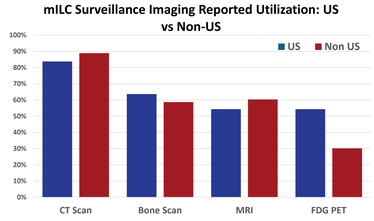
METHODS AND COHORT

- **Survey** – Distributed via LBCA newsletter and social media
- **1706** Respondents with ILC or mixed ILC--70% from US, 11% from UK, 6% from Australia, 5% from Canada, and 8% from 26 other countries
- **1496** respondents diagnosed with early-stage disease (I-III) who have completed active local treatment, and **210** respondents currently living with metastatic ILC (mILC)
  - 40% diagnosed De Novo metastatic; 60% diagnosed with distant recurrence
- Mean age of respondent = 60 (range 33-90)
- Mean age at diagnosis (early stage) = 56 (range 32-89)
- Mean age at diagnosis (mILC cohort) = 55 (range 31-80)
- **88%** stage 1-3, **12%** stage 4
- **70%** of respondents indicated they had dense breasts

QUANTITATIVE RESULTS

Surveillance Reported in US vs. Non-US Cohorts





Breast Imaging Frequency and Additional Components of Surveillance Plans Reported from Respondents with ES ILC:

- In the US, 565 respondents with ES ILC report regular breast imaging for surveillance. Outside of US, 353 respondents with ES ILC report regular breast imaging.
- *Mammogram Frequency as Part of Surveillance?:* In US, 88% report annual frequency, with remainder getting mammograms every 6 months. Outside of US, 92% report annual frequency. If not annual, frequency varied from 6 mo. to every 2 years.
- *Clinical Breast Exam as Part of Surveillance?* 87% of US based respondents reported having regular clinical breast/chest exam as part of their surveillance compared to 69% of non-US respondents.

Additional Surveillance (i.e., blood tests) Reported from Respondents Living with mILC:

US based number of mILC respondents =147

- Additional surveillance blood tests in the US included: regular CBC (94%), CMP blood tests (88%), tumor marker tests (74%), some form of liquid biopsy test (45%)

Non-US based number of mILC respondents = 63

- Additional surveillance blood tests outside of the US included: regular CBC (91%), CMP blood tests (11%), tumor marker tests (73%), some form of liquid biopsy test (6%)

Q: At any time in your care, have you or your doctor attempted to get scans or tests for you but were unable to get them?

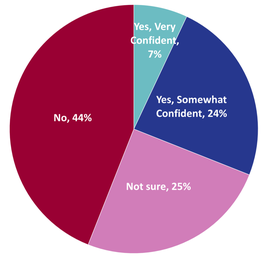
- In the US, 12% of ES respondents reported they were unable to get a test or scan at some point. Reasons for this included 55% reported insurance would not cover and for 39% they wanted but doctor would not order.
- Outside of the US, 23% of ES respondents reported they were unable to get a test or scan at some point. Reasons for this included 54% reporting they wanted a test but the clinician would not order, and for 16%, the test was not available at the local hospital or care center.

Fear of Recurrence (FCR) or Progression (FCP)

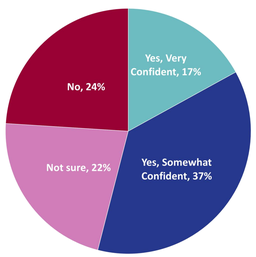
- **81%** of ILC respondents with high (FCR) (8–10) were **not confident** or were **unsure** that surveillance would detect recurrence.
- **49%** of mILC respondents with high FCR lacked confidence that imaging would detect progression.
- Among early-stage ILC breast cancer respondents, surveillance that included breast imaging in addition to mammography (e.g., breast MRI, CEM, or ultrasound) was associated with higher degrees of confidence that the surveillance plan would detect a recurrence.

Patient Confidence in Surveillance Plans

Respondents with Early Stage ILC Were Asked: Are you confident that the current plan for surveillance will detect a lobular recurrence or a new breast cancer?



Respondents Living with mILC Were Asked: Are you confident that the current plan for surveillance will detect a progression?



Survey respondents were asked to comment on why they selected any given level of confidence. For those with no confidence, several key themes emerged.

- Among those with **early-stage ILC**, who said they were not confident in the imaging aspect of the surveillance plan, most felt they needed to self-advocate for something more or different from what their surveillance plan called for.
- Among those living with **metastatic ILC**, mistrust in imaging used in current surveillance plans and the fact that it often did not find the cancer initially or failed to find previous progressions were common themes among those with no confidence.

"I know it's hard to detect and am always fearful that it is still in me somewhere."

"From my own research, I understand how different this cancer presents itself, and I know that it is more common to have a later recurrence than from ductal. I also don't think most clinicians understand the difference, and what they should really be looking for."

"I routinely have symptoms of progression before it is visible on MRI or CT scans."

"It wasn't picked up for 3 years of imaging prior to diagnosis therefore de novo."

DISCUSSION AND DEDICATION

- Respondents reported generally **low confidence** in current surveillance plans.
- High **fear of cancer recurrence** was strongly linked with low confidence in surveillance plans not specific to lobular breast cancer.
- Differences in reported imaging and surveillance modalities used between US and non-US countries suggest **practice variations.**
- **Clear, consistent, and ILC-specific surveillance plans and tools are needed** so patients feel safer, better supported, and more confident that surveillance methods will detect recurrence or if they have metastatic ILC, progressions will be detected.
- Limitations of study: Survey respondents self-selected and responses relied on patient recall.

LBCA and the entire survey team dedicate this work to two of our friends who lost their lives to metastatic ILC before this could be presented. Julia Katherine Levine and Christine McKay were integral to the design of this survey study and were fierce advocates for change and identification of ILC-specific care for those living with a metastatic ILC diagnosis. We are grateful for their vigilant advocacy and sorry they are not here to see this work be completed. We miss them dearly.

