



Individuals with Invasive Lobular Carcinoma (ILC) Raise Their Voices About ILC and Surgery

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What we learned:

More ILC-Specific Info is Needed to Aid Surgical Decision-making & More Research is Needed to Identify ILC-Specific Treatments and Better Methods of Detection

Background

The Lobular Breast Cancer Alliance (LBCA) is committed to raising awareness and promoting research for invasive lobular carcinoma (ILC). In June 2023, LBCA conducted a survey of individuals with ILC about their experience with surgery.

The survey asked about pre-operative imaging, surgical decisions, margins, and included open-ended questions. Results demonstrated that patients had concerns about the extent of disease and risk of recurrence resulting from surgical decisions. Survey analysis will be presented at SABCS 2023.

In addition to responding about surgical experience, respondents had the opportunity to provide an open-ended response related to their experience with ILC and surgery. 1031/1482 respondents provided comments and permission to share. The open-ended comments were reviewed and categorized by the authors. We were incredibly moved by the volume of individuals who commented, and the variety and pathos of their remarks. We felt compelled to honor and give voice to these respondents.

Responses reviewed fell under one or more of six categories:

1. ILC-specific information is needed (N=274),
2. Breast density and ILC diagnosis (N=36),
3. Challenges with surgical decision making (N=266),
4. Better imaging/detection needed (N=224),
5. ILC-specific treatments needed (N=132),
6. Concerns about follow-up and recurrence (N=63).

“On my initial visit with a breast oncologist at a highly regarded cancer center, my knowledge of ILC was more comprehensive than hers thanks to medical journals and the LBC Alliance.”

“I was never told by my team of any need or recommendation to obtain regular scans after an ILC diagnosis... then I was stage 4... I can’t help but wonder if my recurrence would have been found before spreading so far.”

“I was absolutely terrified that the type of cancer I had could be lingering elsewhere in my body.”

“My team provided very little info about ILC and I felt very much on my own.”

“I do still worry about whether I should have had a double mastectomy because of the stories I hear of cancer being discovered in the breast upon surgery/pathology that was otherwise not detected.”

“Not one clinician I’ve encountered has ever mentioned lobular to me- it’s always been me who has raised it.”

“I wish I would have understood that risk of positive margins can be higher so I would’ve been better mentally prepared for needing multiple surgeries.”

“I had 2 mammograms saying I was fine... There should be more extensive testing when you have dense breast tissue. I was lucky.”

“My surgery was originally classified as prophylactic, actual ILC found on pathology.”

“Now concerned about places ILC may metastasize further that may not be picked up on scans.”

“My ILC turned out to be much more extensive than expected and clear margins were not achieved despite cutting out almost half of my breast. I ended up having to have a mastectomy. An MRI might have indicated I needed a mastectomy from the beginning.”

“I knew I had breast cancer 2 years before diagnosis but the doctor refused to do an ultrasound despite the dense breasts.”

“I was never satisfied that they had all of the cancer as every time I had surgery they found more that hadn’t showed up on mammogram.”

Conclusions

It is clear from the sentiments of the 1,031 respondent’s comments that ILC complicated their surgical experiences and that it is extremely critical that ILC receives the research attention that it needs.

Acknowledgments

Dedicated to the memory of Deborah Mueller.