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Invasive Lobular Breast Cancer: 6 Things To Know

Medically reviewed by Maybell Nieves, M.D. Written by Christina Nelson, M.D.

Posted on October 5, 2023

Invasive lobular breast cancer — technically called invasive lobular carcinoma (ILC) — is the second most common type of breast cancer in the United States. Unfortunately, it's not as well-researched as the most common, invasive ductal carcinoma (IDC). ILC is also harder to detect early and more likely to be diagnosed at more advanced stages.

If you or a loved one has been diagnosed with ILC, read on for six important facts you should know about invasive cancer, which begins in the lobules of the breast.

1. The Meaning of 'Invasive Lobular Carcinoma'

Medical terminology can be daunting, but learning more about the terms associated with your diagnosis can help you feel more confident in discussing it with your doctor.

Invasive

The word "invasive" describes the behavior of the cancerous cells in ILC. With this condition, cancerous cells are outgrowing their original location and starting to invade (move into) nearby parts of the breast where they don't belong.

Lobular

The word "lobular" refers to the area of the breast where cancerous cells develop. ILC starts in the lobules, which are milk-producing glands in the breast.

Carcinoma

A cancer is called a "carcinoma" when it forms in epithelial cells, which line the body's organs. Overall, carcinomas are the most common type of cancer.

2. The Symptoms of ILC and Where It Tends To Spread

Until 2015, health experts grouped invasive ductal carcinoma and ILC under the same umbrella term: invasive breast cancer. However, there are several differences between ILC and IDC including:

- The original location of the tumor
- What area in the body the cancer tends to spread
- Common symptoms

First, ILC and IDC begin in different parts of the breast. IDC starts in the milk ducts, and ILC starts in the lobules. The milk ducts are attached to the lobules and carry the milk to the nipple for breastfeeding.

ILC and IDC tumors also behave differently. For example, ILC tends to spread to the ovaries, uterus, stomach, small intestine, and colon. IDC, on the other hand, tends to spread to the liver, bones, and brain. Also, ILC has a higher potential for bilaterality compared to IDC, meaning the cells have a higher risk of spreading to the healthy breast.

People with IDC are more likely to have classic symptoms of breast cancer, such as a lump in the breast. On the other hand, people with ILC may notice dimpling in the breast skin or that certain areas of their breast may feel especially thick.

3. Why Mammograms Are Less Accurate for ILC

Mammograms aren't fully accurate in detecting or estimating the size of ILC tumors. This can make it more difficult for doctors to diagnose breast cancer and recommend the best treatment options.

Diagnosis

Mammograms are the most common test for routine breast cancer screenings to detect cancer in the early stages. A mammogram is an X-ray of the breast used to visualize the breast tissue.

However, ILC is difficult to see on a mammogram and ultrasounds and is often missing during routine screenings. By the time it's finally diagnosed, the tumors may be larger and the cancer may be in a more advanced stage.

In ILC, the cancer cells grow in single file lines and don't form a lump or mass like other breast cancers. This gives ILC a subtle appearance on mammography. Since it doesn't make nearby structures look distorted, a doctor may miss or misinterpret ILC in a mammography. Scientists have found that mammography detects only 34 percent of ILCs — as compared to 81 percent of IDCs, according to the journal Breast Cancer Research.

Tumor Size and Treatment Options

Even when mammography does find ILC, it may underestimate the size of the tumor. The estimated tumor size influences treatment decisions, such as whether breast-conserving surgery or mastectomy should be recommended. Tumor size also influences whether or not doctors recommend chemotherapy before surgery. If tumor size is underestimated, those who need chemotherapy beforehand may not get it.

MRI, another type of imaging technology, is best for detecting ILC. Breast MRIs detect ILC 93 percent of the time, according to Breast Cancer Research. They're also better than mammograms at estimating the size and extent of ILC tumors. This is helpful in treatment planning.

4. The Risk Factors for ILC

Risk factors for ILC include:

- Lobular carcinoma in situ (LCIS)
- Certain genetic mutations (changes) some people are born with

- Some types of hormone replacement therapy (HRT)

LCIS is a noncancerous breast condition. It's diagnosed when abnormal cells are found in the lobule. These cells look the same as breast cancer cells seen in ILC. However, they haven't invaded the surrounding breast tissue. People with LCIS have a higher risk for breast cancer in both breasts.

Scientists have found that women born with a mutation in a gene called CDHI have a 40 percent to 60 percent risk of developing ILC in their lifetime, according to the nonprofit Facing Our Risk of Cancer Empowered. Some types of HRT — which is used for treating symptoms of menopause — can increase a person's risk for risk of breast cancer in general.

5. How Hormone Receptors Can Help With Treatment Options

As part of a biopsy — which entails removing a tissue sample for study under a microscope — cancer cells are tested for details to determine their molecular subtype. In many cases, ILC cells are found to have genes for hormone receptors, such as the estrogen receptor and progesterone receptor. This means the cells rely on specific hormones to grow and spread.

According to the Breast Cancer Research Foundation:

- 95 percent of ILC tumors have the estrogen receptor gene — that is, are ER-positive.
- 70 percent of ILC tumors have the progesterone receptor, meaning they're PR-positive.
- 60 percent of ILC tumors are ER-positive and PR-positive.

If your ILC is ER-positive and/or PR-positive, your oncologist may recommend hormonal treatment. Tamoxifen (sold as Soltamax) is an example of a hormone-blocking medication that is used in lobular breast cancer. (Hormonal treatment for breast cancer is completely separate from HRT.)

ILC tumors are rarely positive for another receptor known as the human epidermal growth factor receptor 2 (HER2) protein. However, targeted treatments for HER-2-positive cancers are available.

Your breast cancer pathology report will show details about your cancer cells such as which receptors are present, as well as the stage and grade of your ILC.

6. The Prognosis for ILC

If you or a loved one has been diagnosed with ILC, understanding the prognosis (outlook) is vital. Prognosis is a prediction about what course a disease will take and how long a person will live after being diagnosed.

The prognosis for ILC largely depends on the stage of your cancer. Breast cancer stages range from 0 to 4, with 0 as the earliest stage and 4 as the most advanced. Stages are sometimes rendered with Roman numerals, for example, stage II instead of stage 2. Staging is a complex assessment that includes:

- Size of the tumor
- Whether cancer has spread to the lymph nodes
- The extent to which the cancer has spread to other parts of the body

The five-year relative survival rate is the likelihood that someone with ILC will still be alive five years after being diagnosed with ILC compared to someone without ILC. The five-year survival rate for ILC is:

- Nearly 100 percent if treated at an early stage
- 93 percent if cancer has spread nearby
- 22 percent if cancer has spread widely in the body

Whether or not your cancer cells have the receptors described above also influences your prognosis because it determines which treatment options may be effective.

People with breast cancers that are ER-positive, PR-positive, and HER2-negative and that have low levels of a protein called Ki-67 tend to have a good prognosis. The prognosis is worse for those with ILC that's HER2-positive without ER or PR hormone receptors.

Talk to your oncology team about your prognosis and which treatment options will work best for you.

Talk With Others Who Understand

MyBCTeam is the social network for people living with breast cancer and their loved ones. On MyBCTeam, more than 65,000 members come together to ask questions, give advice, and share their stories with others who understand what it's like to have been diagnosed with breast cancer.