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# Breast density is a risk women need to know about, cancer survivor group says

Women not informed about breast density level, which is a risk factor for cancer



Radiologist Paula Gordon, a University of British Columbia clinical professor and medical adviser to Dense Breasts Canada, said it is “patronizing” not to notify women of this risk factor associated with breast density. (JEFF VINNICK FOR THE TORONTO STAR)

By **MICHELE HENRY** Staff Reporter

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When Naomi Pickersgill was diagnosed with breast cancer in 2014, it was a shock.

Just 35 days earlier, a mammogram scan of her breasts had come back normal.

It was only after an offhand remark by a specialist prompted her to research on the internet, that Pickersgill found out her mammogram, given as part of the Ontario Breast Screening Program, may not have revealed her cancer due to the density of her breasts.

The 54-year-old Stratford woman's breasts were more glandular than fatty, making it difficult for radiologists to spot the tumours.

Like dense tissue, tumours also appear solid and white on a mammogram.

Pickersgill, who later had a mastectomy and is undergoing cancer treatment, was never told that her mammogram report indicated she had "close to a high density breast." No one told her that this put her at an increased risk for developing breast cancer or that alternate screening tests were available, she said.

"If I had known then maybe I could have been more proactive," she said. Among her options would have been to seek out an MRI or an ultrasound, two tests that are better at detecting cancer in dense breasts.

"I wasn't empowered as a patient."

Pickersgill isn't alone. Her voice joins those of other women who believe their breast cancer may have been missed by mammogram due to the dense tissue. They say that without knowing about this risk factor, they were unable to advocate for themselves.

Breast "density is one of the strongest risk factors for breast cancer," according to Cancer Care Ontario, the Ontario government's principal adviser on cancer and chronic kidney disease care in the province. The problem, the Star found, is that if a woman has a breast density of just under 75 per cent, the patient is usually not told.

It is widely known, according to several experts the Star spoke with, that women with the densest breasts are twice as likely as women with average density to develop breast cancer. For them, mammography can be less accurate at finding their cancers.

In Ontario, women between 50 and 75 years old who have mammograms are notified by mail, and provided a fact sheet on breast density, if the tissue in their breasts is 75 per cent or more fibroglandular rather than fatty tissue. The fibrous tissue blocks X-rays more than fat. These women are also recalled for a mammogram every year, as opposed to the screening program's standard of every two years, and the value of this is also questioned by critics who say that another mammogram a year later may not be the best solution.

But there is no protocol in the province mandating that women be informed by the breast screening program about density that is below 75 per cent but still high enough to raise a concern.

Across Canada, standards vary by province. Doctors in some provinces are provided with more information than in other provinces. Some doctors might share the information with their patients. Others may not.

Dense Breasts Canada, a group of breast cancer survivors and health-care workers dedicated to raising awareness about breast density, is fighting for mandatory notification of breast density across the country, to both patients and their doctors.

They are also pushing for a breast ultrasound for patients whose breasts are greater than 75 per cent fibroglandular tissue. Currently, this additional test, which is less susceptible to breast density's masking effects, is not part of the provincial screening program. Instead, patients are sent for another mammogram one year earlier than normal.

Jennie Dale, Dense Breasts Canada co-founder, said women can be lulled into a "false sense of security" when negative mammogram results arrive in the mail. Failing to inform women about their breast density is like "withholding information that can affect their lives," she said. "It's kept a secret. This is about your health. It's your right to know."

Radiologist Paula Gordon, a University of British Columbia clinical professor and medical adviser to Dense Breasts Canada, said it is "patronizing" not to notify women of this risk factor.

Doctors regularly disclose other risk factors that could lead to further testing, such as measures of cholesterol and blood pressure, she said, adding that breast density is as strong a risk factor for breast cancer as is family history.

Knowing the level of their breast density may prompt women to take better care of themselves, conduct self-exams more regularly, perhaps watch their weight and exercise, which could mitigate an increased risk of developing breast cancer," Gordon said. "It's information women need to know."

In terms of additional testing for dense breasts, Gordon said there is ample research showing that a breast ultrasound detects cancers missed by mammograms and that the earlier these cancers are found the greater the options for treatment. And the better the prognosis for the patient.

In British Columbia, where Gordon practices, breast density, captured by a radiologist under that province's screening program, is not communicated to the patient or her doctor. A high density score likewise does not trigger a mail-out fact sheet or more frequent screening.

According to Cancer Care Ontario, radiologists interpreting mammograms as part of Ontario's breast screening program do not grade each breast for specific levels of density. Rather, they only note whether a breast is over or under 75 per cent fibroglandular tissue, simply ticking off one of two boxes: "Breast density  $\geq$  75%" or "Breast density  $<$  75 %"

On mammograms performed outside the confines of the screening program — mammograms used to locate known tumours, or screens requested by women who are not in the screening program — radiologists may score breasts on a four-point scale, according to radiologist Jean Seely, executive member of the breast imaging working group for the Canadian Association of Radiologists and chair of the newly created Canadian Society of Breast Imaging, an organization designed to provide advocacy and standardization across Canada for breast imaging.

The ratings on that four point scale range from a) “almost entirely fatty” to d), “the breasts are extremely dense, which lowers the sensitivity of mammography.”

But those scores, including c) “the breasts are heterogeneously dense, which may obscure small masses,” are not routinely communicated to the patient, Seely said.

In the U.S., 30 states have adopted breast density notification laws, making it mandatory for doctors to discuss the issue with their patients and tell them if they are above 50 per cent breast density, according to U.S. radiologist Debra Monticciolo, chair of the Commission on Breast Imaging for the American College of Radiology.

Dr. Derek Muradali, head of Breast Imaging at the University of Toronto and radiologist-in-chief for the Ontario Breast Screening Program (OBSP), told the Star in an interview that he is “not quite sure of the rationale behind” the U.S. notification laws.

While he agrees mammograms are “not perfect” and breast cancers can hide in dense tissue, he doesn’t support more or different testing simply because a woman has dense breasts — something he said fluctuates over time (breasts typically become fattier with age, he said).

He said about 10 per cent of women in the provincial screening program have breasts that are 75 per cent or more glandular tissue.

Doctors can send patients for different kinds of tests if they are deemed high risk, have the BRCA gene that indicates a family history of breast cancer, or if there’s an aberration on the mammogram that merits further investigation, he said.

If these high-risk women can’t have an MRI, another test to screen for breast cancer that is not susceptible to the effects of density, for medical reasons (they may not be able to tolerate the dye injection) they can have an ultrasound, Muradali said. “Apart from this, based on the scientific literature, there is no reason to perform a screening breast ultrasound,” he said.

According to Cancer Care Ontario, there is “insufficient evidence” to recommend a breast ultrasound or MRI for women other than those at high risk for breast cancer.”

Muradali said his concern is that extra testing could lead to “false positives” and “harm,” such as needless biopsies and worry.

On informing women of their breast density, he said: “If women are informed of breast density they should be informed of it such that they shouldn’t experience any anxiety because of it.”

Martin Yaffe, a University of Toronto professor and cancer researcher at Sunnybrook Health Sciences Centre who has been studying breast density for 25 years and helped develop Ontario’s breast screening guidelines, said the province should take a common-sense approach and develop guidelines for supplementary screening, which include testing with breast ultrasound or MRI.

He said that since mammograms tend to be less accurate at detecting cancers in women with dense breasts, doing them more frequently — as in, every year as opposed to the screening program’s

every two years — is “not the right answer.”

Yaffe suspects that the cost and availability of supplementary screening may have something to do with the province’s reluctance to make additional testing part of the protocol. Right now, the only way for a patient to have additional screening is for them to “push” for it, he said. “Women have to do their own homework and be their own advocates.”

In December Just over a month after her mammogram indicated she was in the clear, Pickersgill noticed swollen lymph nodes in her neck. Her cancer, diagnosed as invasive lobular carcinoma, a less common form of breast cancer, had already metastasized, she said. She had a single mastectomy a few months later, and a second mastectomy a year later.

It wasn’t until she heard the oncologist talk about density briefly, in the winter of this year, that Pickersgill said she marched into her family doctor’s office and demanded to see her file.

Flipping through the pages, she noticed that in 2012, when a mammogram detected cysts in one breast, a radiologist noted she had some density in both of her breasts. She was sent for a screening ultrasound. She trusted that her doctors were telling her everything she needed to know and were doing all they could.

While her cancer has spread to her spine, it is under control right now and still treatable. But it could take over and take her life at any time, she said.

“Find out what your breast density is,” she said. “If you do have dense tissue, you need to be aware of it. We need to be aware of our bodies.”

Another women’s experience shows the importance of more detailed screening.

When Jodie Sonnenburg, 49, an elementary school teacher in Ottawa, felt a lump in her right breast in March 2016, she told her doctor, who sent her for a mammogram. The test came back clear. Knowing her mammogram was negative, she didn’t panic when, a few months later, Sonnenburg noticed the lump under her arm was making her skin dimple slightly differently. “Again, I wasn’t worried,” she said. “I had done my due diligence by having my annual mammogram, right?”

This time, her doctor sent her for an ultrasound. Immediately after performing the ultrasound test, the technician took her over to the mammography machine. Two weeks later, she met with her doctor who shared the results. The ultrasound showed her tumour but the mammogram on the same day did not pick it up. A few weeks after that she was diagnosed with invasive breast cancer.

Sonnenburg said she always knew she had dense breasts, but she didn’t know what that meant or that it was a risk factor.

“Knowing that my breasts were so dense, why wasn’t I offered an ultrasound in the first place?” she asks now. “Had I known the correlation, I would have most certainly insisted. It could have been caught so much earlier.”

Jennifer Young, president-elect for Ontario's College of Family Physicians, said that physicians are all different when it comes to communicating information to patients, and deciding what information to discuss. Likewise, all patients are different, she said, and have varied desires for information. Young said physicians try their best to establish a relationship with each patient and use that to guide what to talk about.

"I have not read any studies that convinced me that I need to increase a woman's anxiety about her breasts if I don't have to," she said about discussing the issue of notifying women about moderate breast density. Young said she does believe women should be notified about density over 75 per cent. "There's enough stuff out there that people can feel anxious about," she said.

The Canadian Task Force on Preventive Health Care is slated to release new breast cancer screening guidelines in 2018. The task force is not in a position to comment until the guidelines are completed and released, an email to the Star from the task force, said.

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