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Prophylactic mastectomy: When is it the right decision?



It is estimated about 60 women a year in Canada get their healthy breasts cut off to prevent future breast cancer.

by Alison DeLory

HALIFAX | For her entire adult life, Andrea Sylvester (not her real name) has feared getting breast cancer. Her mother, three of her aunts and her grandmother have all had breast cancer. She has had several lumps herself, although ultrasound and needle biopsy have proven them benign.

Sylvester, who is 38 and lives in Halifax, believes she is at high risk for the disease—despite the reassurance of eight clean mammograms. She also had a breast reduction and the removed tissue was tested and found to be healthy.

She does meet the requirements for genetic testing in Nova Scotia and has enrolled

for BRCA analysis. She has been told to expect to wait a year for the test and the results could take another six months. Sylvester will use that time to think about what she will do if it is found she does have a genetic mutation and a high likelihood of getting breast cancer. She said she would definitely consider prophylactic mastectomy.

“It would have to be a strong case (for risk reduction). It’s so difficult with your breasts because they’re such a part of your sexuality. Actually losing my breasts? If it really meant that I was going to be able to prevent breast cancer, I would do it,” said Sylvester.

A Mayo Clinic study performed in 2001 showed that prophylactic removal of both

breasts reduces the risk of a subsequent breast cancer by 89.5% to 100% in women known to be carriers of mutations in the BRCA1 and BRCA2 susceptibility genes.

But does the surgery still make sense for a woman with an unknown risk of acquiring the disease? There is evidence that not all women who want the surgery have had BRCA analysis, and a handful of them seek—and receive—prophylactic mastectomies based on fear alone.

Limitations of testing

Some women don’t meet the criteria for genetic testing in their home province. Others may not pursue the tests because of the limitations of

“Some women have prophylactic mastectomies because of a cancer phobia.” —Dr. Kelly Metcalfe (PhD)

genetic testing. It can’t determine definitely who will and who won’t get cancer, and having the test may make it harder for women to qualify for extended health or life insurance.

There is also the concern that a false negative result could have the unfortunate effect of giving women an unrealistic sense of security. Whatever their reason, women who have not had BRCA analysis do not have an evidence-based assessment and doctors must decide if their patients’ breast cancer anxiety has sufficient repercussions to justify prophylactic mastectomy.

‘Weighing risks’

There appears to be no consensus among clinicians as to whether such women should qualify for surgery or whether counselling could help them gain a realistic understanding of their risk—and affect their desire to have their breasts removed.

Dr. Ivo Olivotto, a leader in radiation oncology at the B.C. Cancer Agency and Screening Mammography Program of British Columbia in Vancouver, said: “Essentially, a woman needs to weigh her risks of developing breast cancer . . . against the risks of harm from doing the surgery and the value she places on her breasts.

“I don’t think a woman has to prove she is at high risk and certainly it is not contingent on her proving that she has a deleterious BRCA1/2 mutation,” Dr. Olivotto continued.

“The important thing is for the woman to have a realistic, rather than fear-inflated, estimate of her risk of developing breast cancer, ideally presented as an absolute risk over the next 10 years.”

According to Dr. Steven Narod, director of the Familial Breast Cancer research unit at Women’s College Hospital in Toronto, the risk of getting breast cancer is about 80% for a woman with a positive BRCA1 or 2 mutation and a strong family history of the disease, about 25% for women with a negative BRCA1 or 2 mutation and a strong family history of the disease, and about 7% for the general population.

“I think many physicians are ill-equipped to assist women to arrive at realistic risk estimates and to interpret those risks,” Dr. Olivotto said.

The surgery is “largely being done at the request of women because of a fear of breast cancer,” said Dr. Narod, adding there is no rule saying you need genetic testing and no guidelines that restrict prophylactic mastectomies. But in Dr. Narod’s experience, to better understand their risks, more than 90% of women will undergo genetic testing before making the decision to have their breasts removed.

Dr. Kelly Metcalfe (PhD), an assistant professor of nursing at the University of Toronto, has published several papers with Dr. Narod about prophylactic bilateral mastectomy for breast cancer prevention. She and Dr.

see **Qualifying** | page 38

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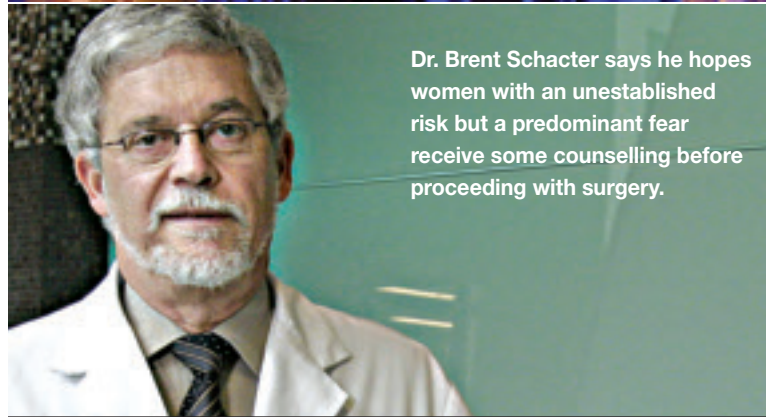
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A woman's risk of getting breast cancer is about 80% if she has a positive BRCA1 or 2 mutation and a strong family history of the disease, says Dr. Steven Narod.



Dr. Brent Schacter says he hopes women with an unestablished risk but a predominant fear receive some counselling before proceeding with surgery.

Qualifying for BRCA testing varies

from | page 37

Narod are following about 300 cases of prophylactic mastectomies performed in Canada and internationally.

"I would like to see BRCA testing a prerequisite of surgery," said Dr. Metcalfe. "Right now, anyone can have it. Some women have prophylactic mastectomies because of a cancer phobia. We need to look at it critically, on a case-by-case basis."

Dr. Brent Schacter works in internal medicine at the University of Manitoba and is CEO of the Canadian Association of Provincial Cancer Agencies

(CAPCA).

Dr. Schacter said he, too, would prefer risk be assessed in an objective, evidence-based way. He also raised the point that some women may not want to stop at the mastectomy but may also consider prophylactic oophorectomy because ovarian cancer is also a risk for many patients with BRCA1 and 2 mutations.

Changing one's appearance

"There are very tough decisions for people positive for the gene. In the end, it's a very personal decision as to whether you're going to take your chances or

whether you're going to basically change how you appear to the world and to yourself," he said.

In Canada today, not all women with a cancer phobia qualify for genetic testing.

Whether a woman qualifies for BRCA testing depends upon the province in which she lives, explained Dr. Metcalfe.

However, there are some common qualifiers, including a family history of cancer—especially gynecological cancers—spanning multiple generations, young onset of cancer among family members and ethnic predisposition to breast cancer, such as Ashkenazi-Jewish lineage.

Wait times for BRCA testing also vary across the nation, with one year being typical in smaller cities. In centres with multiple testing clinics, such as Toronto, wait times can be much shorter.

Dr. Metcalfe estimated women seeking the surgery are, on average, in their early 40s. In Ontario, from 1991 to 2000, there were about 10 prophylactic mastectomies performed each year, according to Dr. Metcalfe. Since the late 1990s, when BRCA testing became available, the number of prophylactic mastectomies performed in Canada has probably doubled, said Dr. Narod.

If this is true and the ratio of prophylactic mastectomies performed in Ontario can be extrapolated to the population of Canada, that would mean about 60 women each year in Canada are having their breasts cut off preventively.

Dr. Schacter explained there is no one maintaining statistics on prophylactic mastectomies, but as CEO of a national cancer agency, he would "guesstimate" there are between 50 and 100 performed annually in Canada.

Currently, about 22% of Canadian women with identified BRCA1 or 2 mutations opt to have the surgery. Worldwide, the rate is 18%, and in the U.S., it's about 35% said Dr. Narod.

Of the approximately 300 women in Canada and abroad who have had the surgery and whose cases Drs. Narod and Metcalfe have followed in the last decade, none have developed breast cancer and overall they report a high level of satisfaction with the decision to have their breasts removed. Dr. Metcalfe said of the 60 or so women she has studied closely, "no one has regretted having it done."

Anxiety without a mutation

"Most women who want the procedure have a BRCA1 or 2 mutation and a strong history of breast cancer. But some women are just very afraid of cancer. They're thinking of cancer every day. They have psychological discomfort. The surgery can directly alleviate anxiety, sleeplessness and depression. I recognize psychological distress as an indication," said Dr. Narod.



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