



Helping women navigate breast cancer decision

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It ranks as one of the most difficult decisions a woman can face: whether to cut off her breasts to prevent cancer cells from infiltrating the tissue.

And it's one that continues to press upon Kelly Metcalfe. The University of Toronto nursing professor has devoted her research career to helping women navigate the hard choices that come with preventing breast cancer, the second biggest cancer killer of women in Canada.

Metcalfe is just beginning to be recognized for her groundbreaking work, which experts in the field say will garner international attention this year.

When Metcalfe, now 37, joined Women's College Hospital as a newly graduated nurse in 1997, the field of breast cancer prevention had just cracked open. Scientists had recently found two predictive genes for the disease, which led to the first genetic tests to determine risk.

Women who tested positive for the BRCA-1 and BRCA-2 genes were told they had an 80 per cent chance of developing breast cancer. They also were told their best chance of survival was to have their breasts surgically removed.

Metcalfe says her nursing background helped her to see the non-medical challenges that women faced.

Despite studies that showed prophylactic mastectomy did prevent cancer, not much was known about how much the drastic surgery might impact a woman's quality of life.

"We knew very little about the psychosocial implications," she recalls. "People thought it was something so barbaric – how could a woman remove her breasts?"

Metcalfe focused her PhD research on answering that question, and found that women who made informed, considered decisions were okay with having their breasts removed if it gave them a longer life.

She has since developed a "decision aid" that helps high-risk women choose which measures they want to take to prevent breast cancer. It is the first of its kind.

"Most of the women we see in genetic clinics are young," she says. "They're in their 30s and 40s and never had breast cancer ... They're not sure what the right decision is for them.

"I can't make a decision for a woman. Her genetic counsellor can't, her physician can't. It's ultimately up to her. Everyone has different values about what's important to them."

Metcalfe says the preliminary results are promising: women who use the decision aid are satisfied with their ultimate decision – whether surgery or careful watch-and-wait. Other health regions – and other countries – are looking to use it.

Researchers now know that roughly 1 in 200 women have a mutation in either the BRCA-1 or BRCA-2 genes. An Ashkenazi Jewish woman has a 1 in 50 chance of having a mutation.

Often the mutations run in families, with breast and ovarian cancer attacking mothers, sisters, daughters, aunts and grandmothers. Though reluctant to draw conclusions from her past, Metcalfe knows what this is like. Her mother died of breast cancer when she was 19.

Three years ago, after her first son, Thomas, was born, Metcalfe herself took the genetic test.

"I'm negative," she says. "Before, you think, if I get cancer and die it will be okay. But once you have a child, that all changes."

Metcalfe and her husband, Richard Patterson, a social worker at the Centre for Addiction and Mental Health, recently welcomed another son, Colin.

But she says she won't take much time off from her research.

Too much – new study results, expanded use of the decision aid, more

awards – is coming out in 2009.

She is now looking at why more women don't opt for preventive surgery.

There are big differences across the country, she says, in the number of women who choose to have their breasts or ovaries removed. In Quebec, for example, few women have prophylactic mastectomy.

And that, she says, must change.

"Our ultimate goal is to prevent as many women as possible from dying from breast cancer. I think we're making progress."