Women with strong family history of breast cancer, no genetic link, are not fully utilising services to their reduce ris

September 25 2011

Women with a strong family history of breast cancer, but no genetic link, are not consistent in how they perceive their risk or in their efforts to manage the risk, leading some women to not adequately access breast cancer services, a University of Melbourne study has found.

The study was led by Dr Louise Keogh from the Centre for Women's Health, Gender and Society in the School of Population Health at the University of Melbourne and published in the journal *Hereditary Cancer in Clinical Practice.*

The aim of the study was to explore how women at higher-than-average risk of breast cancer, without a known genetic mutation perceived and managed their risk. The women were recruited from a population based sample.

Around 5 percent or 300,000 Australian women have a moderate or potentially high risk for breast cancer due to family history with no identified genetic explanation.

"Depending on their family history, these women have up to a 1 in 3 chance of getting breast cancer which is much higher than the population risk of 1 in eleven. Yet there was little consistency in how these women regarded their risk and managed it," Dr Keogh said.

The 24 women in the study had at least one first- or second-degree relative diagnosed with the disease before age 50, and some had up to three first degree relatives diagnosed with breast cancer. None had a BRCA1 or BRCA2 mutation identified in their family.

"Our study revealed that a woman can consider herself to have a '1 in 3' chance of getting breast cancer, but believe she is not the 'one' who will get cancer in her family, while another may interpret a '1 in 3' chance of getting cancer, to mean that she will definitely die of breast cancer," she said.

The women displayed several different 'risk management styles'. These included 'vigilant' prevention behaviour including undergoing annual routine screening (mammography, breast self-examination and clinical breast exams), to what women themselves referred to as a more 'slack' attitude, with little or irregular screening behaviour and finally a fatalistic approach of "it's inevitable so why bother?"

"The majority of the women did not have a regular specialist to assist them to manage their risk, relying solely on their GP and/or an occasional specialist," she said.

"Because a genetic mutation has not been identified to explain the pattern of breast cancer within their family, the women I spoke to were often left to their own devices to manage their high risk, both the anxiety that it can provoke and in identifying appropriate ways to manage their risk.'

"This is not about criticizing services but about raising awareness of the issues faced by some high risk women, and attempting to better understand why they all do not utilise breast cancer services and interventions to reduce their risk," she said.

Dr Alison Trainer, a clinical geneticist with a specialist interest in familial cancer from the Royal Melbourne Hospital said the study indicated a gap in awareness in women at high risk of how to interpret and manage their risk, and of the services available to them.

“Women at high risk can obtain recommendations from specialised familial cancer services throughout Australia about when to commence mammograms and how often to have them, based on their own family history, but it appears very few women in the study had accessed this tailored advice on screening.’

“With the introduction of Medicare funding for breast surveillance by MRI as well as the option of risk reducing medication for women at a high risk of breast cancer, we have increasingly more effective ways of helping women manage their risk and we would encourage women who believe themselves to be at an increased breast cancer risk and their GPs to contact Familial Cancer Centres,” she said.

Heather Drum and Gerda Evans, consumer advocates for Breast Cancer Network Australia (BCNA) have both had breast cancer and belong to high risk breast cancer families. They believe this research is valuable because it demonstrates the need to raise awareness of the services which could help high risk families reduce their risk of developing the disease.

“A woman of 30 in a high risk family needs very different interventions to that of an over 50 year old. The study shows these women need help in finding out about those services, which is a challenge for us representing high risk families in BCNA,” Gerda Evans said.

“I coach a Dragon Boat paddling team called DAM Busters - Dragons Abreast Melbourne. The team is made up of women affected by breast cancer. We have been able to not only support each other in our

experiences but also share information about how to reduce risk. Knowing the services that are out there and living a full active life can help you deal with living with high breast cancer risk," Heather Drum said.

Some interventions for reducing the risk of breast cancer include regular screening, exercise, limiting alcohol, not smoking and maintaining a healthy body weight, plus risk reducing surgery and risk reducing medications for those at very high risk.

Provided by University of Melbourne

Citation: Women with strong family history of breast cancer, no genetic link, are not fully utilising services to their reduce ris (2011, September 25) retrieved 25 April 2024 from https://medicalxpress.com/news/2011-09-women-strong-family-history-breast.html

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