Health and self

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When women receive a breast cancer diagnosis they face choices not only about their immediate treatment, but also about how to manage the risk of recurrence. For a growing number of women that involves surgery to remove a healthy breast.

A study by health economist and Research Fellow at UTS's Centre for Health Economics Research and Evaluation (CHERE) Richard De Abreu Lourenco seeks to understand what factors influence this choice.

"My broader research looks at how we 'value' the experience of health care and how people engage with the health care system beyond just what it does to our health – things like convenience and control," De Abreu Lourenco says.

"With breast cancer, sometimes a decision isn't just about what it's going to do to a woman's health, but about the implications for other aspects of her life – how she feels about herself, her appearance, whether she feels constantly under threat from this cancer coming back."

It's the latest in breast cancer-related research that has been conducted over the years by CHERE, a Centre of Excellence known for its policy-relevant research which is celebrating its 25th anniversary this year.

Throughout his project, De Abreu Lourenco was guided by two patient representatives Kim Parish and Domini Stuart. The pair was an integral part of the research team, ensuring the research remained patient relevant.

In the first stage of the project, De Abreu Lourenco met with breast cancer survivors who shared what mattered to them in making treatment choices.

"Those focus groups were a very enlightening first step because there were aspects people hadn't really thought about," he says.

One of the most important was the big difference in "cancer fear" between women who removed their healthy (contralateral) breast and those who didn't after a diagnosis of cancer in their affected (ipsilateral) breast.

"Women who chose not to remove their contralateral breast really couldn't understand why the women who did remove the breast were so afraid of the cancer coming back," De Abreu Lourenco says. "So there was a very large difference in motivating factors."

That set the scene for the second stage of his research, which involved a survey of nearly 500 women (only 3.5 per cent of whom were breast cancer survivors).

The women were presented with a series of choices, which varied each time, and asked to decide whether in those circumstances they would remove their healthy breast or have routine monitoring only.

"The first big result that hits you is how many women have a very strong preference one way or the other," De Abreu Lourenco says. Regardless of how he adjusted the parameters, nigh on 60 per cent of the women stuck with their original choice.

Just over 49 per cent always chose routine monitoring, while 8.4 per cent always chose surgery, no matter how the choices were framed.

The remainder of the women were willing to 'trade' depending on the scenario, sometimes selecting routine monitoring and sometimes choosing surgery.

What influenced those choices, most of the time, was the perceived risk of the cancer returning.

When De Abreu Lourenco evened out that risk in the choice questionnaire – making it the same regardless of surgery or monitoring – other factors then emerged.

"The way they were monitored became important," he says. "Women wanted a less invasive type of monitoring – they wanted ultrasound rather than a mammogram."

Involvement in decision making also emerged as a key factor. De Abreu Lourenco says his study has implications for how we inform women of their choices, especially when data suggest only a marginal improvement in long-term life expectancy from contralateral prophylactic mastectomy (CPM).

"One of the things that will hopefully come out of this is that it will help to frame education pieces," he says. "Does CPM represent the value that people think it does? Or could that money be better spent in other ways?"

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