High Cost Drugs Research Project

'I might chose to sell my house, get help from family members... there are a lot of women in the public system with money who might be able to afford it, so never make assumptions. Every woman has the right to know the best options and decide what’s right for her.'

In 2008 Breast Cancer Network Australia (BCNA) undertook a research project with researchers from the University of Sydney. We wanted to know if women with breast cancer would like their oncologists to discuss expensive (or high cost) breast cancer drugs with them, even if they may not be able to afford them.

Recent research had shown us that as many as 40% of oncologists in Australia would not discuss a high cost drug with a woman, if they thought she could not afford it, for fear of causing distress to her or her family.

To date however, researchers had not asked women what they want. We thought it was important to find out what kind of information women would like to hear from their oncologist about high cost drugs.

BCNA worked in partnership with Honours student, Emily Kaser and researchers from the University of Sydney to ask women about their views.

What did we do?

Three hundred and seventeen women from BCNA’s Review and Survey Group, all of whom have experienced breast cancer, were invited to be involved in the research. Forty seven women took up the invitation and participated in a telephone survey.

What did we find?

'My doctor is very upfront about things. He’s not warm and fuzzy, but he’s very consistent and that is very reassuring.'

Overwhelmingly, women told us that they wanted to know about high cost drugs where they may be a suitable treatment option, even if they may not be able to afford it.

Women said that information around treatment choices was far more important than any potential distress caused if they could not afford the treatment.

Some women added that they would like their oncologist to check with them first about how much information they wanted to know about high cost drugs.
While the research team considered high cost drugs to be those that cost thousands of dollars, women said that any drug which left them more than $50 per week out of pocket is to them, a high cost drug.

In addition, we also found that:

- Women said that discussing their financial situation was less concerning compared with many of the other sensitive topics discussed with their doctor.

- 28% of women had discussed a high cost drug with their oncologist previously and all had been able to access the treatment through a range of different strategies.

- Making assumptions about women’s treatment preferences, and withholding information from women about treatment options, were behaviours that were viewed very negatively by the women.

- Women preferred that their doctor was honest about all treatment options, and that they were transparent and direct during any discussions about treatment options.

Conclusions

‘In an ideal world it would be great if your doctor found out how much you wanted to know before diving in.’

BCNA believes that doctors need to offer women quality information and discuss treatment options with women, including asking about the how much information they would like to know.

Women with breast cancer want their doctors to be honest and direct with them about the range of treatment options, to enable them to make informed choices about their treatment.

The findings of this research highlight the importance and value of asking women what they think about issues. Often women’s perspective can be very different from that of healthcare professionals.

Next steps

‘Doctors shouldn’t make judgements on whether or not women, rich or poor, can afford a drug – we should all be given the opportunity to use the drug rather than shutting the door and making assumptions.’

BCNA will now promote these findings to oncologists to encourage them to discuss the range of treatment options with women.

The results from this research are being used to develop a communication skills training program for oncologists and health professionals working with women with breast cancer.