

“It felt like unfinished business, it feels like that’s finished now”
A research study exploring women’s experiences of decision making
around Contralateral Prophylactic Mastectomy (CPM)

Why did we do this research?

Increasing numbers of women in the UK are choosing to have a Contralateral Prophylactic Mastectomy (CPM) after diagnosis of breast cancer, and research suggests that many experience high rates of psychological wellbeing after CPM. However, professional guidelines suggest CPM is ‘not required’ for the majority of unilateral breast cancer patients and some individuals consider the surgery to be controversial. Existing research has explored patients’ reasons for seeking CPM, however, little is known about their experiences of decision making. This study aimed to investigate women’s experiences of decision making around CPM.

What did we find?

Twenty-seven women took part in telephone interviews, recruited through ‘Flat Friends’ and ‘Breast Cancer Care’.

Women described being met with resistance when initiating discussions about CPM with healthcare professionals and referred to the process of requesting CPM as a ‘fight’ or a ‘battle’. Whilst some were pleasantly surprised at the willingness of their clinicians to consider CPM, others reported a far longer and more challenging process, at what was already a very difficult time. Women were often asked to see a psychologist as part of their decision-making process. Whilst some women found this helpful, others suggested that this could be stigmatising and could increase feelings of isolation. Women who did not want breast reconstruction after CPM also reported feeling this consultation as discriminatory. Many women joined online forums or social media groups for others who had been diagnosed with breast cancer and were reassured that their thoughts regarding CPM were similar to others.

An important element of the decision-making process for many women was considering the relationship they wished to have with their body in the future and how this might be sought through CPM. For some women this was about symmetry, and for many women who did not want breast reconstruction symmetry was an

important factor in moving forward after treatment; whilst for others it was about addressing the psychological distress that they associated with their remaining breast and a distrust in available surveillance methods.

The results of this study highlight the importance of open communication by healthcare professionals, the role of peer support in decision making, and the need for healthcare professionals to fully understand the potentially complex nature of each woman's decision to seek CPM.

What next?

We are in the process of publishing these results in an academic journal ('Psycho-oncology'), where we hope they will be read by surgeons, nurses and other healthcare professionals who work with women considering CPM. We also hope to present these results at conferences in summer 2019, to tell people directly about our research and the findings.

We would also like to apply for funding to conduct further research in this area, specifically focusing on outcomes for women who choose to have CPM without reconstruction.

How do I find out more?

If you have any questions about this research or our findings, please contact Dr Pippa Tollow at the University of the West of England (pippa.tollow@uwe.ac.uk; 0117 32 87389).