Why women are choosing mastectomy: influences beyond the surgeon

AUTHORS: Covelli, Andrea M.¹ MD, PhD; Baxter, Nancy² MD, PhD; Fitch, Margaret³ MScN, PhD; Wright, Frances³, MD, MEd

INSTITUTIONS: 1. Institute of Health Policy, Management and Evaluation at the University of Toronto, Toronto, ON, Canada.  
2. Li Ka Shing Knowledge Institute at St. Michael's Hospital, Toronto, ON, Canada.  
3. Odette Cancer Centre at Sunnybrook Health Sciences Centre, Toronto, ON, Canada.

Background: Rates of both unilateral (UM) and contralateral prophylactic mastectomy (CPM) for early stage breast cancer (ESBC) have been increasing. Surgical decision making is comprised of the surgeon, the patient and the external environment. We sought the perspectives of patients who chose UM +/- CPM and treating surgeons to understand why mastectomy rates have been increasing.

Methods: We completed a grounded theory qualitative study to examine the surgeon’s practice and the patient’s decision making that resulted in the choice for UM +/- CPM. Purposive sampling identified women across Toronto, Canada who were suitable candidates for breast conserving therapy (BCT) but underwent UM +/- CPM. Academic and community breast surgeons from across Ontario, Canada and the United States were also recruited. Data were collected through semi-structured interviews, this continued until data saturation was reached. Constant comparative analysis identified key ideas.

Results: 29 patients and 45 surgeons completed interviews. The dominant theme was ‘Desire for control’, women strived to improve their cancer outcomes by undergoing more extensive surgery. Surgeons described BCT and UM as equivalent treatment options for ESBC, and frequently recommended BCT. Despite this, surgeons described women initiating the request for UM+CPM. In this average risk population CPM was discouraged by the surgeons describing no survival advantage and increased operative risks.

The most influential factor in a woman’s request for CPM was their personal cancer experiences with family and friends and not the surgical consultation. A previous negative experience with breast cancer translated into an overestimated risk of recurrence, contralateral cancer and subsequent mortality. Women chose UM+CPM to ensure they would ‘never go through this again.’ Despite feeling confident in their choice most women had ongoing issues with disturbed skin sensation, cosmesis and body image.

Conclusion: Despite surgeon’s recommending against it, a previous cancer experience is extremely influential in women choosing UM+CPM. As many women had long term pain and issues with cosmesis after UM +/- CPM, we suggest women may benefit from education including exposure to other patients’ post-operative concerns to aid in their decision making.