

TITLE: Taking control of cancer: Why women are choosing mastectomy

AUTHORS: Covelli, Andrea M.¹; Baxter, Nancy²; Fitch, Margaret³; Wright, Frances³

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 bilateral mastectomy (BM) for early stage breast cancer (ESBC) have been increasing since 2003. Studies suggest that this is due to women playing a more active role in their decision making, however they do not describe why women are choosing this option.

Methods: We conducted a qualitative study using grounded theory to identify factors influential in women's choice for mastectomy. Purposive sampling was used to identify women across the Greater Toronto Area (Ontario, Canada), who were suitable candidates for breast conserving surgery (BCS) but underwent UM or BM. Data were collected through semi-structured interviews. Constant comparative analysis identified key ideas and themes.

Results: Data saturation was achieved after 29 in-person interviews. 12 interviewees were treated at academic cancer centres, 6 at an academic non-cancer centre and 11 at community centres. 15 women underwent UM; 14 underwent BM. Median age was 55.

'**Taking control of cancer**' was the dominant theme that emerged. There were 7 subthemes: 1. the **Diagnosis** of cancer was received with shock and fear; 2. during **Surgical Discussion** both BCS and UM were discussed; BM was discouraged by the surgeon 3. women **Misperceived Risk**, misunderstanding recurrence and survival rates 4. **Women's choice for UM** was due to fear of recurrence and/ or radiation 5. **Women's choice for BM** was due to fear of recurrence, 'never wanting to do this again' and/or need for cosmetic balance 6. **Sources of Information** varied in importance, previous cancer experience had the greatest impact 7. women were actively **Controlling Outcomes**, more surgery was seen as greater control

Conclusion: Women seeking UM and BM for treatment of their early stage breast cancer manage their fear of recurrence and 'never wanting to go through this again' by undergoing more extensive surgery. The patient's effort to control the cancer outcome is the driving factor behind women choosing mastectomy.