

Choosing Mastectomy:  
A Qualitative Exploration of the Increasing Mastectomy Rates in  
Women with Early-Stage Breast Cancer

by

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Institute of Health Policy, Management and Evaluation

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# Choosing Mastectomy: A Qualitative Exploration of the Increasing Mastectomy Rates in Women with Early-Stage Breast Cancer

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## Abstract

**Context:** Rates of Unilateral (UM) and contralateral prophylactic mastectomy (CPM) for early-stage breast cancer (ESBC) have been increasing. Numerous factors for this rise have been suggested including the surgeon's preference, the patient's choice and the external environment.

**Objectives:** A grounded theory study explored women's decision-making processes in their treatment for ESBC, and elucidated the role of the surgeon and the practice environment in the increasing rates. The Health-Belief Model was applied, discerning those factors influential in surgical decision-making shaping women's choice for UM+/-CPM.

**Design:** Semi-structured interviews were conducted with patients to understand their experiences and decision-making which resulted in undergoing UM+/-CPM. Similarly, semi-structured interviews were conducted with general surgeons exploring their treatment approaches to ESBC. Theoretical sampling identified suitable candidates. Data were collected until saturation was reached. Constant comparative analysis identified key concepts.

**Results:** 29 patients and 45 surgeons completed interviews. **The ‘overwhelming threat’ of breast cancer** ‘was the dominant theme. Despite surgeons describing the high survivability of ESBC, patients misperceived the threat of death from their cancer, and strived to eliminate this threat by choosing UM+/-CPM. Surgeons described breast-conserving therapy (BCT) and UM as equivalent treatment options for ESBC, and frequently recommended BCT. Despite this, women requested UM+/-CPM. CPM was discouraged, as surgeons described no survival advantage and increased operative risks.

Experiential knowledge was the most influential factor in patients’ decision-making. Previous negative experiences of family and friends with breast cancer, translated into an overestimated risk of recurrence, contralateral cancer, metastasis and subsequent death. Patients’ perceived the risks and severity of ESBC to be great, and believed that by choosing UM+/-CPM they would eliminate the threat of breast cancer. Most women did not perceive any risks of undergoing UM+/-CPM, yet many experienced concerns with disturbed skin sensation, cosmesis and body image.

**Conclusion:** Previous cancer experiences and experiential knowledge are extremely influential in women undergoing UM+/-CPM. Women overestimated their risk and misperceived the benefit of UM+/-CPM as they thought it would substantially improve their cancer outcomes. As undergoing UM+/-CPM is not without risks improved discussion of patient sources of information and fears around survival may benefit surgical consultations, facilitating informed decision-making.

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## List of Abbreviations

Bilateral Prophylactic Mastectomy	BPM
Breast Conserving Surgery	BCS
Breast Conserving Therapy (Breast Conserving Surgery and Radiation Therapy)	BCT
Breast Self-Examination	BSE
Common Sense Model	CSM
Contralateral Breast Cancer	CBC
Contralateral Prophylactic Mastectomy	CPM
Decision-Aids	DA
Early-Stage Breast Cancer	ESBC
Grounded Theory	GT
Health-Belief Model	HBM
Immediate Breast Reconstruction	IBR
Informed Decision Making	IDM
Magnetic Resonance Imaging	MRI
National Cancer Institute	NCI
National Comprehensive Cancer Network	NCCN
National Institute of Health	NIH
Precaution Adoption Process Model	PAPM
Radiation Therapy	RT
Randomized Control Trial	RCT
Shared Decision Making	SDM
Social Cognitive Theory	SCT
Society of Surgical Oncology	SSO

Socioeconomic Status	SES
Surveillance, Epidemiology and End Results	SEER
Theory of Planned Behaviour	TPB
Theory of Reasoned Action	TRA
Transtheoretical Model	TTM
Unilateral Mastectomy	UM
Unilateral Mastectomy with Reconstruction	UM+R
United Kingdom	U.K.
United States of America	U.S.

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## Chapter 1- Introduction

Despite wide consensus that breast-conserving surgery is a safe, effective approach for the treatment of early-stage breast cancer (ESBC), rates of unilateral mastectomy (UM), after declining for more than a decade, have recently been increasing. Similarly, the rates of contralateral prophylactic mastectomy (CPM) for the treatment of unilateral ESBC are increasing despite no recommendations endorsing its use in women who are not at high-risk of developing contralateral breast cancer. Neither UM nor CPM offers an increased survival benefit, yet the rate at which women are undergoing these surgeries continues to increase. While survey studies have attributed the increased mastectomy rates to women playing a more active role in their surgical decision-making, these studies do not describe the factors women are now considering in their decision-making process. Other studies have suggested that both the surgeon, as well as treatment-related factors such as use of MRI and access to reconstruction, may be playing a role in the increasing rates. While multiple studies have illustrated the changing surgical rates, it remains unclear which factors are influencing this trend and how they translate into women undergoing mastectomy for the treatment of early-breast cancer.

The purpose of this study is to explore the current surgical decision-making process for women with ESBC, and to elucidate those factors which might be influential in the decision-making process resulting in women undergoing UM and CPM. This study is important as provides an understanding, and framework, upon which we can address the current process of surgical decision-making for early-stage breast cancer, thereby having a practical impact on patient care. Understanding the factors influencing decision-making for early-stage breast cancer is key to developing strategies to improve the ability to facilitate informed decision-making.

## Chapter 2- Background

### 2.1 Surgical Treatment for Early-Stage Breast Cancer

Early-stage breast cancer (ESBC) is defined as stage 1 or stage 2 disease that is, tumours up to 5cm in size confined to the breast with or without ipsilateral nodal involvement, or tumours greater than 5cm without nodal involvement (AJCC Cancer Staging Manual, 2010). In the early 1900s Halstead introduced the en-bloc resection of the breast, regional lymphatics, and pectoralis muscles (what is known as radical mastectomy) for the surgical management of breast cancer. In the 1930s the modified radical mastectomy was introduced with the argument that sparing the pectoralis muscle would not significantly alter survival, but would lessen surgical and long-term morbidity (Cotlar, Dubose, & Rose, 2003). Removing just the tumour itself (segmental mastectomy/ lumpectomy) and the axillary lymph nodes in women with stage 1/2 breast cancer was first performed in the 1970s (Cotlar et al., 2003). Studies conducted around this time demonstrated no survival difference between women who underwent the radical mastectomy in comparison to a modified-radical mastectomy (Fisher et al., 1985b). In addition, the first prospective study examining outcomes of patients who underwent modified radical mastectomy with those who underwent segmental mastectomy with and without radiation was conducted and equivalent survival across the surgical groups was demonstrated (Veronesi et al., 1981). However, in the mid-1980s these initial study findings only demonstrated a 5 year follow-up and were felt to be insufficient to change practice. This resulted in multiple prospective studies being conducted with further long-term follow-up; these again demonstrated equivalent survival between surgical groups (Fisher et al., 1985a; Fisher et al., 1989; Van Dongen et al., 1992). In response to these emerging findings the National Institute of Health (NIH) developed and released a consensus statement indicating that “breast conservation treatment is an appropriate method of primary therapy for the majority of women with stage 1/2 disease and is preferable because it provides survival rates equivalent to those of mastectomy while preserving the breast” (National Institute of Health, 1991). Breast conserving surgery (BCS) is defined as removal of the tumour, encompassed by a cuff of normal tissue and historically includes three operations: lumpectomy, quadrantectomy, and segmental mastectomy, with lumpectomy being the most commonly performed procedure (National Institute of Health, 1991). In response to the

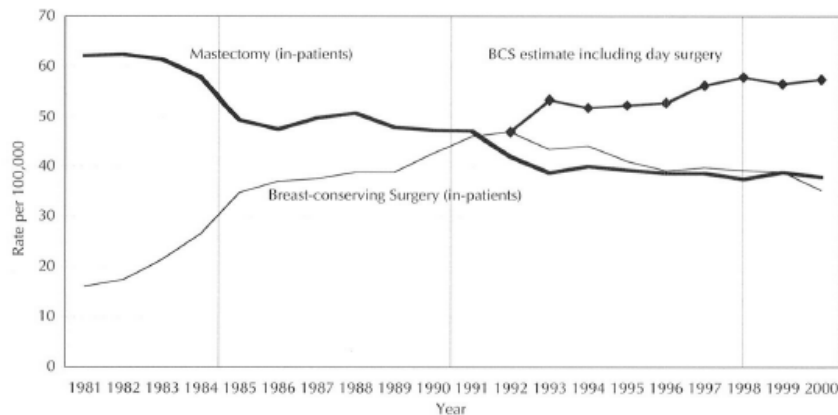
release of the NIH consensus statement, rates of mastectomy began to decrease and breast conserving therapy (BCT, breast conserving surgery followed by radiation therapy) began to increase (Lazovich, Solomon, Thomas, Moe, & White, 1999), with BCT becoming the mainstay of surgical treatment for ESBC (National Comprehensive Cancer Network, 2014c). Over a 90 year period the surgical management for EBSC evolved from extensive removal of the breast, chest wall and axilla, to the minimal removal of the tumour itself and diagnostic/affected lymph nodes, with the intent of reducing women's surgical morbidity.

The recommendation for BCT in ESBC has been widely adopted, and guidelines have been published in the United States (U.S.) Canada, England and Europe (2009; National Comprehensive Cancer Network, 2014c; Scarth, Cantin, & Levine, 2002; Senkus et al., 2013). Canadian surgical guidelines for ESBC were first produced in 1998. These guidelines stated that for ESBC, 'breast conserving surgery followed by radiotherapy is the preferred surgical treatment option in the absence of special reasons for choosing mastectomy' (Margolese, Beaulieu, Caines, Bouchard, & The Steering Committee on Clinical Practice Guidelines for the Care and Treatment of Breast Cancer, 1998). These guidelines were established after long-term follow-up from 6 randomized control trials (RCTs) which demonstrated no survival difference in those women undergoing BCT and women undergoing unilateral mastectomy (UM) for the treatment of ESBC (Arriagada, Le, Rochard, & Contesso, 1996; Blichert-Toft et al., 1992; Fisher, Anderson, Redmond, Wolmark, & Wickerham, 1995; Fisher et al., 1989; Van Dongen et al., 1992; Veronesi et al., 1981). Further follow-up from the initial RCTs demonstrated equivalent 20 year survival, and to-date no significant survival difference has been demonstrated for either disease-related mortality or all-cause mortality between women undergoing BCT and UM (Fisher et al., 2002; Van Dongen, Voogd, & Van Zijl, 2000; Veronesi et al., 2002). In 2002 the Canadian guidelines were revisited, and reinforced that the mainstay treatment for early-breast cancer is breast-conserving surgery plus radiation (Scarth et al., 2002). In addition, the guidelines clearly outlined cases where mastectomy might be considered for the treatment of ESBC, these are listed in TABLE 1 below.

Mastectomy should be considered in the presence of any of the following :	
a.	Factors that increase the risk of local recurrence such as extensive malignant-type calcifications, multiple primary tumours, or failure to obtain tumour-free margins
b.	Physical disabilities that preclude lying flat or abducting the arm thus preventing the use of radiotherapy
c.	Absolute contraindications to radiotherapy such as pregnancy in the first or second trimester or previous irradiation to the breast , or relative contraindications such as systemic lupus erythematousus or scleroderma
d.	Large tumour size in proportion to breast size
e.	The patient's clear preference to mastectomy

**TABLE 1: 2002 recommendations for the clinical practice guideline for the care and treatment of breast cancer: Mastectomy or lumpectomy? The choice for operation for clinical stages I and II breast cancer**

Before the release of the 1991 NIH statement and related surgical guidelines, the majority of women with ESBC were treated with mastectomy. However after 1990 the rates of mastectomy were noted to have decreased markedly across a number of countries including the U.S., Canada, the Netherlands, and England and Wales (de Koning, van Dongen, & van der Maas, 1994; Gaudette et al., 2004; Harries, Lawrence, Scriver, Fieldman, & Kissin, 1996; Lazovich et al., 1999). Within Canada rates of UM declined from to 62.2% to 37.95% between 1981 and 2000, with an inversely related increase in BCT (Gaudette et al., 2004) (FIGURE 1). As illustrated in Figure 1 the decline in Canadian mastectomy rates were closely correlated with the release of the results of the NASBP-06 study in 1985 (1 of the 6 RCTs demonstrating equivalent survival), the 1991 release of the NIH guidelines, and the subsequent release of the Canadian Practice Guidelines (these events are indicated in FIGURE 1 by the solid vertical lines at the years 1985, 1991 and 1998 respectively). While the clinical indications listed in TABLE 1 may preclude some women from undergoing mastectomy, it is estimated that 80% of Canadian women with ESBC are suitable candidates for BCS with radiation (Margolese et al., 1998). As presented in Table 1, in the absence of specific clinical indications precluding BCS, the choice of surgical procedure for the treatment of breast cancer is then dependent upon patient preference (Scarth et al., 2002).



**FIGURE 1:**  
Age standardized rates  
for surgical procedures  
for invasive breast  
cancer, Canada, 1981-  
2000.

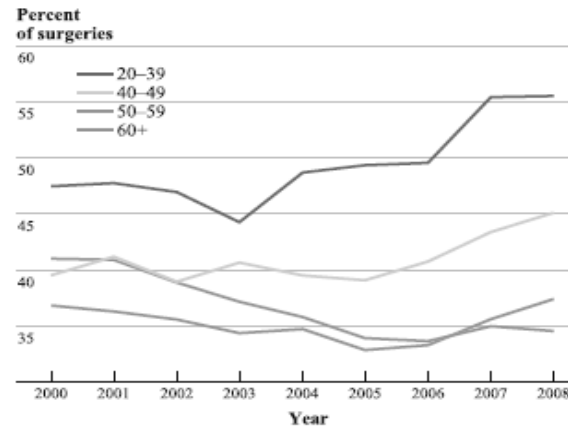
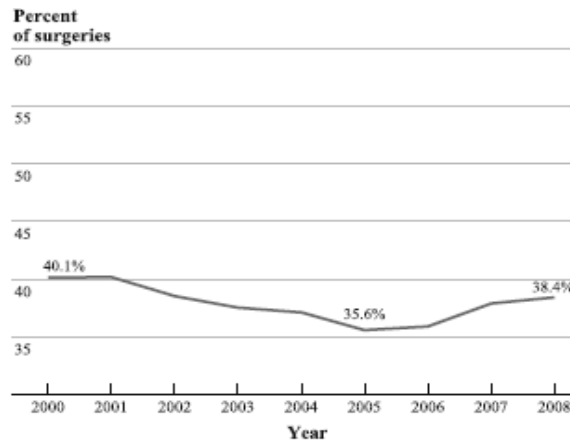
Gaudette et al., *Can J Public Health* 2004, **95**:336-340.

## 2.2 Increasing Unilateral Mastectomy Rates

Since the mid-2000s studies from the U.S., the United Kingdom (U.K.) and Canada have identified an increasing trend towards women selecting mastectomy for the treatment of ESBC (Ballinger, Mayer, Lawrence, & Fallowfield, 2008; Canadian Institute for Health Information, 2012; Dragun, Huang, Tucker, & Spanos, 2012a; Gomez et al., 2010; Katipamula et al., 2009; Mahmood et al., 2013; McGuire et al., 2009). Despite no change in surgical guidelines nor recommendations for the use of UM, this increase has been documented in institutional, state/provincial-wide and nation-wide studies.

A number of academic centres have reported an increase in mastectomy rates between 35%-43% of all women with ESBC between 2003-2007 (Katipamula et al., 2009; McGuire et al., 2009). Similar to these institutional trends, state-wide trends within the U.S. have demonstrated rising mastectomy rates, with overall increases varying from 19% to 43%. (Dragun et al., 2012a; Gomez et al., 2010). State-wide analyses have also illustrated that the increase is largest in women less than 50 years of age. Provincial trends in Ontario demonstrated a 9% increase in mastectomy between 2000 and 2006 (Hodgson, Przybysz, Bhamani, & Urbach, 2006). The most demonstrative illustration of increasing UM rates is the Surveillance, Epidemiology and End Results (SEER, a U.S. national database) analysis of surgical treatment for ESBC between 2000 and 2008. Mahmood et al. (2013) demonstrated there was a significant increase in the use of UM between 2005 and 2008 with an

overall rise in the rate by 10%, again the largest increase being in women less than 50 years of age (FIGURES 2 and 3).



**FIGURE 2:** U.S. national mastectomy rate (2000-2008)      **FIGURE 3:** Mastectomy rate by age at diagnosis

Mahmood et al. *Ann Surg. Onc.* 2013; **20**:1436-1443.

## 2.3 Contralateral Breast Cancer (CBC)

### 2.3.1 Surgical Management and Rates of CBC

In the setting of a unilateral breast cancer, those women who are considered to be at high-risk for developing a contralateral breast cancer (CBC) are recommended to undergo contralateral prophylactic mastectomy (CPM, the removal of the non-cancerous breast). Women who are considered high-risk include those with a personal or familial history of BRCA1/2 or other known genetic mutations including PTEN and P53, a personal history of ovarian cancer, a personal history of chest wall radiation and a strong family history of breast or ovarian cancer (National Comprehensive Cancer Network, 2014b). It is estimated that women who are positive for BRCA1 and BRCA2 have a 43% (BRCA1) and 34% (BRCA2) risk of developing CBC over the ten years following their initial diagnosis, and have a 55% and 38% risk of developing a CBC over the next 25 years (Metcalf et al., 2004; Rhiem et al., 2012). In addition, women from high-risk families who are not positive for the BRCA mutations demonstrate a risk of developing a CBC between 27%-40% over 20 years (Shahedi, Emanuelsson, Wiklund, & Gronberg, 2006). Given this elevated risk, research has suggested that women at high-risk benefit by undergoing UM+CPM. A 20-year

retrospective review of BRCA positive women demonstrated that 33.5% of women who underwent UM developed a CBC, in contrast of those women who underwent UM+CPM only 0.6% developed a CBC (Metcalf et al., 2014). More importantly, 29% of women who underwent UM died from breast cancer, whereas only 9.9% of women who underwent UM+CPM died from breast cancer (Metcalf et al., 2014).

Excluding this high-risk population, women who develop unilateral breast cancer have estimated incidence of 0.5- 1% per year of developing a CBC, and a maximum lifetime risk of 12-15% (Chen, Thompson, Semenciw, & Mao, 1999; Nichols, Berrington de Gonzalez, Lacey Jr, Rosenberg, & Anderson, 2011). The use CPM has not illustrated a survival benefit in the non-high risk population, and it is not recommended that women who are not from a high-risk category undergo CPM (Lostumbo, Carbine, & Wallace, 2010; Peralta et al., 2000; Pesce et al., 2014). A recent U.S. nationwide study comparing overall survival of non-high-risk women who have undergone UM and UM+CPM demonstrated that undergoing UM+CPM offers no survival benefit over those women who underwent UM (Pesce et al., 2014). A Cochrane review of CPM examined 8 meta-analysis in non-high risk women and it was found that while women undergoing CPM had a decrease in incidence of contralateral breast cancer, they did not experience improved survival (Lostumbo et al., 2010). This apparent contradiction is best explained by the risk of mortality from primary tumor metastasis verses the mortality from the potential development of a contralateral cancer. A large 20-year follow-up study of women with unilateral breast cancer demonstrated that the vast majority of breast cancer deaths in women with ESBC were due to systemic spread of the index cancer (21%) whereas development of a CBC, metastasis and subsequent death (presumed secondary to the CBC), only occurred in 0.7% of patients (Rosen, Groshen, Kinne, & Norton, 1993). In addition, while rates of CBC were reported as high as 15% over a ten-year period in the non-high risk population, more recently studies have demonstrated that women who undergo adjuvant therapy (hormonal and chemotherapy) have a reduced risk of CBC (Bertelsen et al., 2008; Forbes et al., 2008). Specifically, the ATAC trial examining the use of hormonal treatments alone, or in combination, demonstrated that the use of hormonal treatment reduced the risk of developing a CBC by 42% in comparison to women who received no treatment (Forbes et al., 2008; Howell et al., 2005). In a twenty-year study Kherelsheild (2011) reported rates of CBC over the twenty-years of follow-up to be 4.4% in non-high risk women. In addition, they reported that the contralateral tumours were significantly smaller



than both contemporary unilateral tumours in women newly diagnosed cancer, as well as the associated initial tumours (Kheirelseid et al., 2011). Also, the rates of survival were the same for women who had a CBC as compared to those who had unilateral cancer (Kheirelseid et al., 2011), suggesting that the development of a CBC is not the cause of death and therefore undergoing CPM does not improve survival.

### 2.3.2 Complications of CPM

Undergoing CPM is not without risk of immediate post-operative complications and potential long-term complications, both which have been associated with mastectomy in the cancerous breast. Known immediate post-operative complications of a mastectomy include minor (those complications that do not require hospitalization or re-operation) and major (those which require hospitalization and/or re-operation) complications. Minor complications consist of wound infections (with rates up to 30%), seromas (with rates up to 26%), hematomas (which occur between 2-10%), tissue necrosis and delayed wound healing (Canavese et al., 1997; Miller et al., 2013; Vitug & Newman, 2007). Major complications include seromas and hematomas which require operative management, tissue necrosis requiring debridement, wound infections which require hospitalization, and bleeding requiring transfusion (Miller et al., 2013). In addition, non-operative site complications can include venous thromboembolism, acute renal insufficiency, cerebral vascular accidents, myocardial infarctions, respiratory distress, and disseminated infection (pneumonia, urinary tract infection, deep space soft tissue infection, sepsis) (Osman, Saleh, Jackson, Corrigan, & Cil, 2013; Vitug & Newman, 2007). Recent studies conducted by Miller et al. (2013) and Osman et al. (2013) have demonstrated that there is an increased risk of post-operative complications in women who undergo UM+CPM. Miller reported that women who underwent UM+CPM had a 2.7 times increased risk of all complications and 1.5 times increase risk of a major complication, in comparison to women who underwent UM (Miller et al., 2013). The most frequent major complication was infection requiring hospitalization (Miller et al., 2013). Miller (2013) also described the laterality of these complications, with 39% of women experienced a complication in the cancerous breast, 37% in the non-cancerous breast and 23% in both the cancerous and non-cancerous breasts, demonstrating that complications in the contralateral breast are just as likely to occur as in the cancerous breast. Osman's (2013) national database study reported similar findings; women undergoing CPM had an overall complication rate 1.9 times greater than women who underwent UM. Specifically, there were

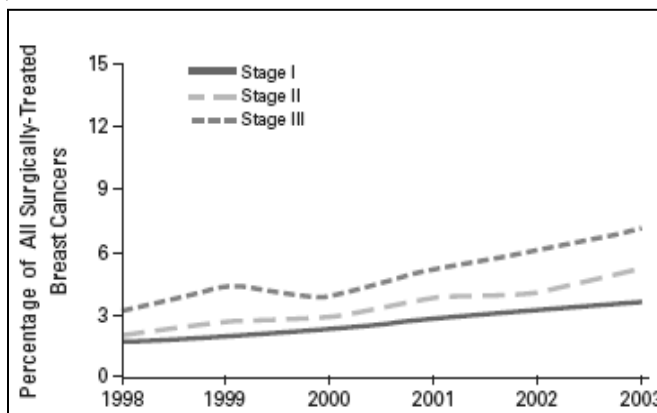
higher rates of local wound infection (2.1 times) and disseminated infections (2.9 times). This increase in infection may be secondary to increased operative times (undergoing UM+CPM requires more operative time than women who undergo just UM), as it has been demonstrated that women who undergo UM are known to have higher rates of both local and disseminated infection than women who undergo BCS (Canadian Institute for Health Information, 2012; El-Tamer et al., 2007; Osman et al., 2013). It is important to note the increased rates of post-operative complications in non-high risk women undergoing UM+CPM as such complications have been related to increased rates of long-term complications, as well as delay in receiving adjuvant therapy (which has the potential to impact overall survival) (Lohrisch et al., 2006; Vitug & Newman, 2007). A recent study conducted by Sharpe et al. (2014) demonstrated that those women who underwent UM+CPM had a longer time to surgery. This translated into a statistically significant longer number of days from diagnosis until definitive adjuvant therapy in those patients who underwent UM+CPM as compared to those who underwent UM (Sharpe et al., 2014).

Long-term post-operative concerns include chronic pain, changes in skin sensation and concerns around cosmesis and body image. Chronic post-operative pain can occur at the site of the incision, throughout the chest wall, as well as into the upper extremity and it can range from mild to debilitating. It is estimated that moderate to severe pain can occur in up to 30% of breast cancer patients (Tasmuth, Von Smitten, Hietanen, Kataja, & Kalso, 1995). Women who undergo breast cancer surgery may also experience long-term concerns around body image and cosmesis. A study on satisfaction in women who have chosen to undergo CPM has demonstrated that even in long-term follow-up, 10% of women are not satisfied with their choice to undergo CPM and would not choose the procedure again (Frost et al., 2011). More markedly reported is that up to 45% of women experienced some adverse effect (with regards to body image concerns or sexuality) from CPM even after 20 years following their procedure (Frost et al., 2011). It has also been illustrated that 6% of patients express regret around their decision, most often due to cosmetic outcomes and changes in sexuality (Montgomery et al., 1999). Currently, there are no guidelines recommending the use of CPM in women with ESBC who are not at increased risk for developing contralateral disease. The Cochrane review suggests that given the lack of evidence of improved survival in non-high risk women, the benefit of CPM must be weighed against the risk of mortality from primary tumour metastasis, in addition to the risk of psychosocial and physical morbidity that has been documented

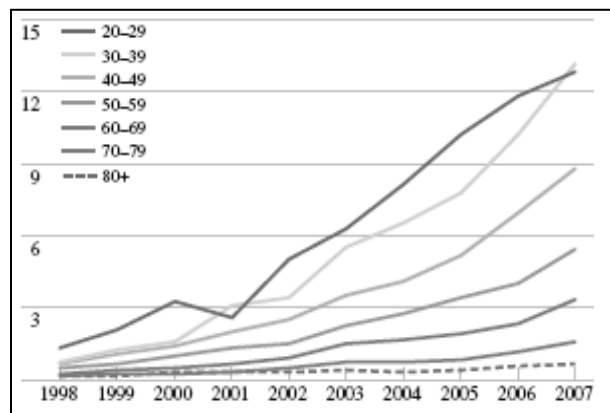
with CPM; thereby recommending against CPM (Frost et al., 2011; Lostumbo et al., 2010; Montgomery et al., 1999).

## 2.4 Increasing Contralateral Prophylactic Mastectomy Rates

Despite the lack of recommendation for CPM in the non-high risk population, in addition to UM there has also been a noted increase in women undergoing elective CPM. Nation-wide studies from the United States using the SEER registries and the National Cancer Database have demonstrated a 150% rise CPM rates since 2000 across all age groups with ESBC in a unilateral breast (Tuttle, Habermann, Grund, Morris, & Virnig, 2007; Yao, Stewart, Winchester, & Winchester, 2010). Tuttle et al.'s (2007) SEER analysis revealed that the rates of women undergoing CPM have more than doubled between 1999-2003 for all stages of breast cancer, including stages 1 and 2 (FIGURE 4). Yoa et al. (2010) continued to demonstrate this increasing trend until 2007 using the American College of Surgeon's National Cancer database; between 1998 and 2007 the rates of CPM rose from 0.4% to 4.7%. Yoa et al. (2010) also demonstrated that this trend across all age groups (FIGURE 5).



**FIGURE 4:**  
**Contralateral Prophylactic Mastectomy**  
**rate(percentage) by stage at diagnosis (1998-2003)**  
 Tuttle et al. *JCO*. 2007; **25**:5203-5209.



**FIGURE 5:**  
**Contralateral Prophylactic Mastectomy rate**  
**(percentage) by age at diagnosis (1998-2007)**  
 Yao et al. *Ann Surg. Onc.* 2010; **17**:2554-2562.

McLaughlin et al. (2009) illustrated a similar trend in use of CPM in their state-wide analysis with rates increasing from 5.6% to 14.1% of all women receiving therapeutic mastectomies between 1995 and 2005. Whereas, Dragun et al. (2012b) demonstrated that even in the rural state of Kentucky, a demographic often omitted from nation-wide analysis, an increase in recent rates of CPM. Between

1995 and 2004 the rate of mastectomy (UM and CPM) remained constant however since 2004 the rate of overall mastectomy rose from 29.8% to 39.5%; within the group of women undergoing mastectomy there was a seven-fold increase in the use of CPM (Dragun et al., 2012b). Multiple institute analyses have also illustrated this phenomenon of increasing CPM rates. Jones' (2009) multiple site analysis illustrated increasing rates of CPM from 6-16% between 2003 and 2007. Similarly, Arrington et al. (2009) reported that of women who were suitable candidates for BCT, 28.9% underwent UM with CPM. Additionally, Yi et al. (2010) reported a 105% increase in rates of UM+CPM between 2000 and 2006. However, the increasing use of CPM has not been limited to just the United States; nation-wide analysis from both Canada and England have also demonstrated a rise in the use of CPM in ESBC by 50% since the mid 2000s (Canadian Institute for Health Information, 2012; Neuburger, Macneill, Jeevan, van der Meulen, & Cromwell, 2013). As presented in TABLE 2, the Canadian Institute for Health Information (2012) has reported rates of CPM increasing by 1% per year of all women undergoing surgery for unilateral ESBC. In 2008 the rate of Canadian women undergoing UM+CPM was 5%, this increased to 7% in 2010 (Canadian Institute for Health Information, 2012). Within the U.K. a multi-institute (National Health Service Hospitals) study reported a 7% increase per year in rates of CPM resulting in an overall increase from 2.1-3.0% for all women with a unilateral breast cancer undergoing CPM between 2002 and 2009 (Neuburger et al., 2013).

	2007-2008	2008-2009	2009-2010
<b>Women who underwent CPM</b>	<b>289 (5%)</b>	<b>363 (6%)</b>	<b>414 (7%)</b>
<b>Total women who underwent mastectomy(ies)</b>	<b>5,892</b>	<b>6,182</b>	<b>6,301</b>

**Table 2: Rates of CPM among Canadian women with unilateral invasive breast cancer who underwent mastectomy(ies) as their initial surgical procedure**

## 2.5 Clinical Management Factors

Clinical management factors can be thought of as those aspects of the health-care practice that might guide and direct the diagnosis and treatment of the index breast cancer. While it not yet understood to what extent each clinical management factors influences the increasing mastectomy rates, contemporaneous to the increasing rates of UM+/-CPM has been the increased uptake and availability in the use of both magnetic resonance imaging (MRI) and reconstructive surgery.

## 2.5.1 Magnetic Resonance Imaging (MRI)

### 2.5.1.1 *The role of MRI in screening and treatment planning*

Since the late 1990s MRI had begun to demonstrate its use for delineating the extent of the tumour, differentiating benign and malignant lesions indistinguishable on mammogram, as well as investigate recurrence at the site of the surgical scar (Esserman et al., 1999; Morris, 2001). In 2004 Kreige et al. (2004) published their landmark trial demonstrating the efficacy of MRI in breast-cancer screening for high risk women. This study demonstrated superior sensitivity (79.5% vs. 33.3%) in comparison to mammogram for detecting early cancers in this high risk population (Kreige et al., 2004; Lord et al., 2007). However Kreige's (2004) study also demonstrated inferior specificity with MRI in comparison to mammogram 89.8% vs. 98.1%. MRI has since been reported to result in a 3-5 fold increased risk of work-ups for false positive results (Kreige et al., 2004; Lord et al., 2007).

Given the increased sensitivity of MRI this technique has been valuable in, and become well-established for: excluding cancer in the setting of equivocal findings on mammogram and ultrasound, diagnosing cancers that present with palpable findings (including axillary metastasis) but are otherwise radiologically occult, differentiating recurrence from a previous BCS scar, and assessing the extent of residual cancer after neoadjuvant therapy (Esserman et al., 1999; Morris, 2001; Morrow, Waters, & Morris, 2011). However, the role of MRI in treatment selection and local management of early breast cancer beyond these indications has been less clearly established. Despite this, the American College of Radiology (2013) recommends that all women with the diagnosis of a unilateral breast cancer undergo MRI for pre-operative assessment of both the index cancer (in the ipsilateral breast) as well as the contralateral breast.

### 2.5.1.2 *Increasing MRI use*

In recent years the rates of MRI for treatment planning subsequent to the diagnosis of ESBC have continued to increase (Esserman et al., 1999; Hulvat, Sandalow, Rademaker, Helenowski, & Hansen, 2010; Katipamula et al., 2009; Miller, Abbott, & Tuttle, 2012; Morris, 2001; Morrow et al., 2011). A study by the Society of Breast Imaging found that 74% of U.S. practices surveyed routinely offer MRI to patients diagnosed with breast cancer (Bassett et al., 2008). Similarly, a number of single

institute studies have demonstrated a rise in MRI use for clinical management of women diagnosed with breast cancer, with use increasing anywhere from 185-733% between 1998 and 2009 (Hulvat et al., 2010; Katipamula et al., 2009; Miller et al., 2012). Katipamula et al. (2009) reported their MRI use increased from 10% to 23% between 2003 and 2006 whereas Miller et al. (2012) reported an increase in MRI use from 9% to 75% of all patients diagnosed with breast cancer between 2002 and 2009.

Increasing use of MRI for treatment planning has been correlated with an increase in the number of patients undergoing mastectomy. In a large meta-analysis MRI identified additional disease in 16% of patients, which resulted in 11% of all women undergoing wider excision or mastectomy as opposed to the originally planned BCS (Houssami et al., 2008). Three large institute studies have demonstrated that women who underwent pre-operative MRI were twice as likely to undergo UM+CPM (Chung, Huynh, Lawrence, Sim, & Giuliano, 2012; King et al., 2011; Stucky, Gray, Wasif, Dueck, & Pockaj, 2010). Similarly, Miller (2012) demonstrated that 51% of patients who had undergone an MRI at their institution had additional positive findings; having undergone an MRI was an independent risk factor and increased the likelihood of undergoing a mastectomy by 1.8 times.

#### ***2.5.1.3 The effect of MRI on additional disease, recurrence and re-excision***

The finding of additional disease on MRI is not necessarily indicative of the need to undergo more extensive surgery. The introduction of MRI has resulted in identifying a much higher rate of additional malignant disease than the historical rates of recurrence in women who underwent BCT, suggesting that not all of these secondary lesions present as future disease (Hwang, Schiller, Crystal, Maki, & McCready, 2009; Morrow et al., 2011; Solin, Orel, Hwang, Harris, & Schnall, 2008). It has been established that average risk women who choose to undergo BCT (including adjuvant treatment) for ESBC have an estimated recurrence rate of 3-7%, lower than would be estimated from the 16% of additional pre-operative malignant lesions on MRI, suggesting that not all of these lesions go on to present as recurrence (Morrow et al., 2011). In addition, a retrospective study examining those patients who underwent surgical planning based on MRI in comparison to those who underwent mammogram demonstrated no reduction in metastasis, CBC, improvement in overall or disease-specific survival with more extensive disease detection (and subsequent resection) on

MRI (Solin et al., 2008). As standard adjuvant therapy is believed to adequately treat such previously unidentified lesions, the role of MRI in identifying these lesions has not yet demonstrated clear evidence of patient benefit.

It has been argued that ipsilateral recurrence following BCS and the need to then undergo delayed (completion) mastectomy might be avoided through the use of pre-operative MRI planning. Two large institutional retrospective studies and one randomized controlled trial have examined the rate of ipsilateral recurrence in those patients who underwent BCS with and without preoperative MRI planning (Hwang et al., 2009; Solin et al., 2008; Turnbull et al., 2010). It was demonstrated that there was no significant difference in ipsilateral recurrence between those who underwent preoperative MRI versus those who did not (3% vs. 4% and 1.8% vs 2.5%) suggesting that microscopic foci seen on MRI are successfully treated with postoperative radiation. Therefore, identification of foci pre-operatively does not impact rates of recurrence and further surgical resection, but may serve to increase the rates of mastectomy (as the initial surgical procedure undergone). Furthermore, a meta-analysis by Houssami et al. (2013) demonstrated that MRI did not improve short-term surgical outcomes (i.e. the need for re-excision of lumpectomies with positive margins) but did increase the overall mastectomy rates.

MRI use has also demonstrated an increase in detection of contralateral breast findings. It is estimated that 3-4% of women diagnosed with breast cancer that undergo MRI for further workup and treatment planning have a contralateral lesion identified (Brennan et al., 2009; Lehman et al., 2007). In Brennan's (2009) meta-analysis the authors demonstrate while up to 4% of women have lesions identified, the capability of MRI to determine whether these lesions are benign or malignant is poor. In addition, 35 to 40% of the contralateral lesions have been documented to be DCIS (Brennan et al., 2009; Lehman et al., 2007). Similar to the ipsilateral findings on MRI, it has not yet been established to what extent identification and subsequent management of these contralateral findings impacts patient outcomes. Large population-based studies have previously demonstrated that the rate of CBC are less than 1%/year in non-high-risk women (Nichols et al., 2011). Again, the increase in contralateral findings on MRI may not present as clinically meaningful findings given both the high proportion of that which is DCIS (and may never present as cancer), along with adjuvant treatment for the primary cancer. Taking this literature together, routine use of MRI in

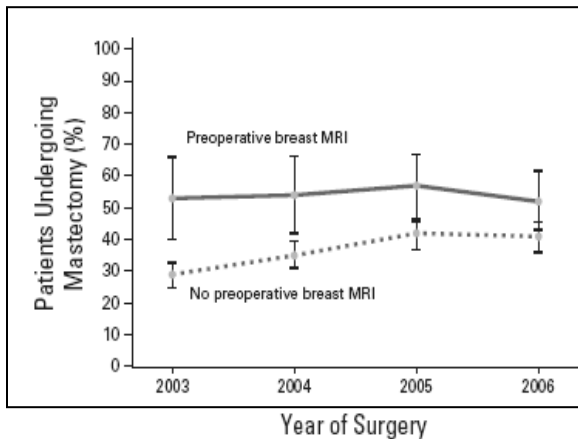
non-high risk women does not reduce the likelihood of re-excision (for positive margins) or recurrence, and may infrequently detect clinically significant additional disease. However, the use of MRI has been associated with increased rates of unilateral and contralateral mastectomy, suggesting that the routine use of pre-operative MRI has an unfavorable risk-benefit ratio (Houssami et al., 2013; Morrow et al., 2011; Solin et al., 2008; Turnbull et al., 2010).

#### ***2.5.1.4 MRI and Increasing Mastectomy Rates***

Although the increase in MRI use may explain some of the increase in mastectomy rates, many women undergoing mastectomy remain excellent candidates for BCS. The widely documented increase in mastectomy rates cannot be explained entirely by the increased use of MRI alone, as the number of women currently undergoing UM+/-CPM exceeds the number which have multicentric disease in the ipsilateral breast or a second cancer in the contralateral breast detected on MRI (Hwang et al., 2009; Katipamula et al., 2009; Morrow et al., 2011; Solin et al., 2008). Katipamula et al. (2009) noted at their institute, that while MRI rates increased from 10% to 23% between 2003 and 2006, the increased mastectomy rates during this time period were predominately in those women who *did not* undergo MRI (FIGURE 6). A significant increase in mastectomy rates, from 29% to 41%, occurred in those women who did not undergo MRI (Katipamula et al., 2009). In Miller's (2012) study, 39% of women who opted for mastectomy did not have additional findings on their MRI (FIGURE 7). Similarly, 38% of women with an MRI finding underwent mastectomy without completing a biopsy to rule-out benign disease, and 31% opted for mastectomy despite a negative biopsy result.

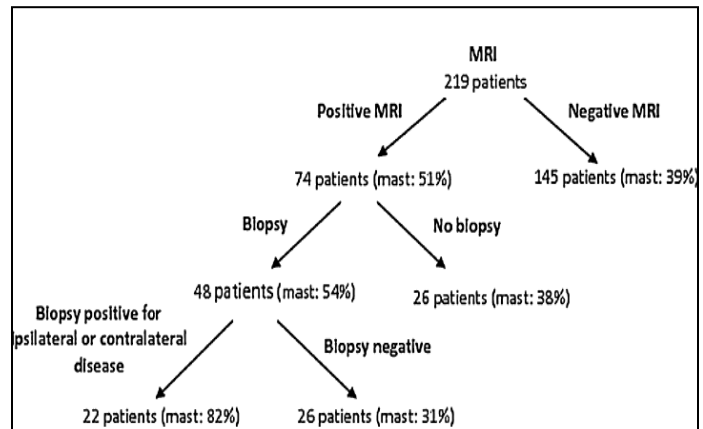
It has been argued that due to the sensitivity of MRI, a negative MRI (i.e. no additional disease) would result in women opting for less extensive surgery however the opposite phenomenon has been demonstrated, with more women opting for mastectomy despite negative findings. The change in mastectomy rates cannot be accounted for by positive disease findings on MRI alone; understanding what role MRI might play in women's decision-making, and why women might opt for mastectomy despite negative cancer findings on MRI needs to be more thoroughly explored.





**FIGURE 6: Proportion of patients undergoing UM from 2003 to 2006 according to utilization of preoperative MRI .**

Katipamula et al.. *JCO.* 2009; **27**:4082-4088.



**FIGURE 7:**

**MRI results and outcomes (mastectomy rates shown in parentheses)**

Miller et al. *Ann Surg Onc.* 2012; **19**:536-540.

### 2.5.2. Breast Reconstruction

While it is not certain to what extent the availability of immediate breast reconstruction (IBR) might influence the surgical decision-making process, a number of studies have demonstrated positive correlations between increasing rates of UM+CPM and immediate reconstruction. A U.S. nationwide study examining reconstruction rates between 1998 and 2008 demonstrated that while the absolute rate of reconstruction increased overall it was most notable for women who underwent UM+CPM, with rates increasing at 3% per year (Cemal et al., 2013). In addition, Cemal et al. (2013) reported an increase in rates of women undergoing UM+CPM by 15% per year, with 59.5% of all women who underwent UM+CPM also undergoing IBR. In contrast, the rates of women who underwent UM+IBR remained relatively unchanged, with approximately 24% of women with UM also undergoing IBR (Cemal et al., 2013). A nationwide SEER database study examining rates of mastectomy and reconstruction reported that between 2004-2008 of all patients who underwent mastectomy 16% had UM+CPM, with 46% also undergoing reconstruction (Ashfaq et al., 2014). Comparatively, only 15% of those women who underwent UM were reconstructed (Ashfaq et al., 2014). In addition, reconstruction was a positive predictor for UM+CPM, with reconstruction increasing the likelihood of woman undergoing CPM by 3.6 times (Ashfaq et al., 2014). In a single institution study Stucky et al. (2010) reported a doubling in reconstruction rates for those women

who underwent CPM between 2000 and 2008. Stucky (2010) also demonstrated that of those women who underwent UM+CPM, 71% also underwent reconstruction, whereas only 33% underwent reconstruction following UM. Similarly, other single institution studies have demonstrated that of those women who underwent CPM, rates of reconstruction ranged from 74.8% to 92.2%, and undergoing reconstruction was associated with an increased likelihood of undergoing UM+CPM by 3-8 times (Chung et al., 2012; King et al., 2011; Yi et al., 2010). A recent U.S. nationwide study has demonstrated that rates of UM+CPM were notably higher at institutes which offer IBR as compared to those institutes which do not offer IBR (Habermann, Thomsen, Hieken, & Boughey, 2014). Of women who underwent mastectomy only 10% underwent UM+CPM at centres that did not offer IBR, in contrast rates of UM+CPM ranged from 16.5%-33.4% of women undergoing mastectomy at centres where IBR was available (Habermann et al., 2014). In addition, the percent of women undergoing UM+CPM increased as the volume of IBR performed increased (with 16.5% at low volume centres, 26.3% at mid volume centres and 33.4% at high volume centres) (Habermann et al., 2014).

While positive relationships between reconstruction and mastectomy have been demonstrated, it has not been clearly established the role that reconstruction might play in the decision-making process for ESBC. However, some studies have suggested that reconstruction may at least in-part, be influential in women's surgical decisions. In a survey study examining women's choices for CPM, 10% of women indicated a desire for symmetry was part of their decision-making (Montgomery et al., 1999). Similarly, an institutional study reported that of women who underwent UM+CPM, 59% considered the availability of the reconstructive surgeon (Soran et al., 2013). A UK study conducted by Beesley et al. (2013) demonstrated that 40% of women described the benefit for symmetry with UM+CPM, in addition to undergoing 'risk-reducing surgery'. Interestingly, in a study examining the role of reconstruction in high-risk (positive BRCA status) women's choice for bilateral prophylactic mastectomy (BPM) 95% of women had a discussion about reconstruction prior to making their decision and 92.5% stated that the reconstructive options made them more willing to consider BPM (Nelson et al., 2012). In addition, women's most influential sources of information for BPM with reconstruction were the breast (oncology) surgeons and reconstructive surgeons, not non-traditional sources such as the media and internet (Nelson et al., 2012). While this high-risk population differs in that their decision-making occurred in the absence of cancer, the potential role the surgeon and

reconstruction may play in the decision-making process for mastectomy is noteworthy and must be better understood in women's choice for UM+/-CPM.

### 2.5.3 Radiation

While delivery of radiation therapy (RT) in the setting of BCS has changed over recent years to include both intra-operative RT and brachytherapy, the mainstay for radiation is 3-5 weeks of radiotherapy 5 days a week following breast surgery (Darby et al., 2011; Haviland et al., 2013). The role that radiation had been documented to play in relation to the choice for mastectomy has been previously attributed to the distance a patient lived from a radiation facility. Nattinger et al. (2001) completed a nation-wide study using SEER data examining the impact that distance from a radiation facility had on mastectomy rates between the years of 1991 and 1992. Nattinger (2001) demonstrated that further distance from a radiation facility resulted in a decreased likelihood of undergoing radiation. Specifically, women who lived more than 15 miles from a radiation facility were twice as likely to undergo UM, and of women who opted for BCS those who lived greater than 40 miles were half as likely to return for RT as women within a 40 mile radius. Furthermore, Nattinger (2001) demonstrated that this effect was not associated with an increasing age. Similarly, more recent state-wide studies have demonstrated that when controlling for other factors, an increasing distance from RT facilities is associated with an increase in mastectomy rates (Menden, St. John-Larkin, Hermes, & Sommerschild, 2002; Schroen, Brenin, Kelly, Knaus, & Slingluff, 2005; Voti et al., 2006). Schroen's (2005) study within Virginia state demonstrated mastectomy rates for women with less than 2cm tumours was 31% when they lived less than 10 miles from a RT facility, but increased to 49% when the distance was greater than 50 miles. Similarly, Voti et al. (2006) demonstrated that the odds of undergoing BCT decreased with each 5 mile increase from a radiation facility and Menden (2002) documented mastectomy rates as high as 85.7% in women who lived more than 45 miles from a radiation facility in northern Michigan. More recent SEER studies conducted by Boscoe et al. (2011) and Jacobs et al. (2008) have demonstrated that living in a rural location, and a distance more than 75km (approximately 46 miles) from a radiation facility increased the odds of undergoing mastectomy from 1.4-1.58 times respectively.

Known morbidity associated with RT includes: radiation pneumonitis, severe lymphedema, impaired shoulder mobility, myocardial dysfunction and skin changes (Senkus-Konefka & Jassem, 2006;

Wood, Shapiro, & Reichtm, 2001). However, with the exception of changes in skin, most of these side-effects are rare (<1%), and even skin-associated changes substantially decrease over time (Wood et al., 2001). In addition, much of the data on radiation side-effects has come from older studies with obsolete radiation techniques contemporary techniques, including the use of hypofractionated RT may provide lower long-term morbidity (Senkus-Konefka & Jassem, 2006). Despite the low-rates of RT associated side-effects, many studies previously reported that patient's may avoid radiation due to fears and misperceptions associated with radiation (Benedict, Cole, Baron, & Baron, 2001; Collins et al., 2009; Elward et al., 1998; Kotwall et al., 1996; Nold, Beamer, Helmer, & McBoyle, 2000). Statewide surveys examining the variation in BCT rates in the early 1990s demonstrated that fears and concerns associated with radiation were influential in a women's choice for UM rather than BCT (Elward et al., 1998; Stafford, Szczys, Becker, Anderson, & Bushfield, 1998). Up to 72% of ESBC patients surveyed by Stafford et al. (1998) described some concerns with radiation, with 60% indicating apprehension around the effects of radiation. Benedict's (2001) study on factors influencing the choice for BCT demonstrated that 17% of women who chose to undergo mastectomy did so due to fear (and not inaccessibility) of radiation. Similarly, in a survey conducted by Nold et al. (2000) examining those factors influential in the choice for mastectomy, patients indicated that 'avoidance of radiation' was one of the most influential factors. In a more recent study examining patients' values in the choice for BCT or UM, Collins et al. (2009) demonstrated that the desire to avoid radiation increased the likelihood of undergoing mastectomy by 1.5 times. Despite previous literature describing both distance to a radiation facility and concerns around the side-effects of radiation influencing the choice for mastectomy, the role that radiation might play on the increasing rates of UM+/-CPM has not been well established.

## 2.6 The Role of the Physician

### 2.6.1 Varying Rates of UM and BCT

Despite studies demonstrating the efficacy of BCS, nation-wide reports conducted in the U.S. demonstrated that rates of BCS in the late 1980s were slow to increase. A population-based study reported the percent of women with Stage 1 disease who underwent BCS increased from 35.9% in 1983 to 43.2% in 1989, and 24.5% in 1983 to 24.4% in 1989 for stage 2 disease. (Lazovich, White, Thomas, & Moe, 1991). A state-wide study conducted by Mann et al. (1988) during this same time

reported that the use of BCS for ESBC increased from 2% to 25% between 1980 and 1985. In this study Mann et al. (1988) demonstrated that part of this rise in BCS was due to the increased adoption of BCS by some of the surgeons studied, with approximately half using BCS in at least 10% of their patients. However, Mann et al. (1988) also demonstrated that the uptake of BCS was quite variable, with some surgeons performing BCS on only one patient and others performing BCS in up to 56% of all patients. While these initially low rates of adoption of BCS were felt to be reflective of the ‘newness’ of this technique and therefore unequal rates of uptake by surgeons, the percent of candidates undergoing BCS remained highly variable even after the release of the 1991 NIH consensus statement. Following the NIH statement release, substantial geographic variation in the use of BCS continued to be reported in the early 1990s in both Canada and the U.S. State-wide rates varied in the U.S. in 1995 from 23.8-74% and provincial-wide rates in Canada varied from 24.8-69.3% (Gaudette et al., 2004; Lazovich et al., 1999). A statewide retrospective review conducted between 1992-1993 demonstrated that within state BCT rates varied between 0-44%, with the average being 20% of all suitable candidates undergoing BCT (Elward et al., 1998). During a similar time-frame, Iscoe et al. (1994) reported notable provincial wide variation in Ontario, with BCT with rates ranging between 11-84% (averaging 52%). Goel et al. (1997) reported the average Ontario rate was 67.6% while British Columbia was 43.8%.

### 2.6.2 Surgeon factors correlated with BCS and UM+/-CPM

While geographic factors (including distance to radiation facility as described above in section 2.5.3) have been attributed to the resultant variation in uptake of BCS, the role of the surgeon has also accounted for some of this variability. Factors including provider preference, extent of training, location of practice and gender had all been described to influence the variation in use of BCS (Benedict et al., 2001; Elward et al., 1998; Goel et al., 1997; Iscoe et al., 1994; Lazovich et al., 1999). Multiple studies demonstrated that younger, female surgeons had higher rates of BCS (Caldon, Walters, Ratcliffe, & Reed, 2007; Cyran, Crane, & Palmer, 2001; Grilli et al., 1994; Hershman et al., 2009; Mandelblatt et al., 2001). Practice-related factors including the location of training, the extent of fellowship training, the year after which medical school was graduated and practicing at a high volume breast centre have also been positively associated with rates of BCS (Chapgar et al., 2006; Hershman et al., 2009; Hiotis, Ye, Sposto, & Skinner, 2005; Katz et al., 2005b; Liang et al., 2002; Woon & Chan, 2005). Hiotis et al. (2005) and Hershman et al. (2009)

reported that patients who were treated at centres with procedure volumes of greater than 71 cases per year and/or a surgeon who performed more than 15 breast cancer surgeries per year, had an increased likelihood of undergoing BCS by 1.2-1.6 times. Similarly, a surgeon who completed a surgical oncology fellowship had been demonstrated to increase the likelihood of BCS by 1.26 times and decrease the likelihood of undergoing UM by approximately half (Hiotis et al., 2005; Woon & Chan, 2005). Iscoe (1994) demonstrated that important predictors for the early-adoption of BCS included working at a hospital that had been part of the NSABP-06 trial or a hospital which was affiliated with a medical school. Similarly, Goel et al. (1997) and Chapgar et al. (2006) found that surgeons who practiced in academic centres had higher rates of BCS.

It is felt that physician practice style, including patient-physician communication and attitudes towards BCS were in-part responsible for the varying rates (Lazovich et al., 1999; Liang et al., 2002; Liberati et al., 1991; Mandelblatt et al., 2001). A study conducted by Deber and Thompson (1987) in 1985 examining why surgeons were still recommending mastectomy (as opposed to BCT) found that despite being aware of the RCTs demonstrating survival equivalence between UM and BCT, UM was still perceived to reduce the patients' overall risk, increase their curability and was overall deemed more effective. In addition, the surgeons in Deber's (1987) study felt that clinical trials were difficult to translate into practice, as they do not take into account the uniqueness of patients. Similarly, a survey study conducted by Tarbox et al. (1992) demonstrated that not all surgeons (22%) believed in the equal efficacy of BCS and therefore did not present them as equivalent options, resulting in a UM rate of 64%. In contrast, those surgeons that presented BCS and UM as equivalent treatment options had a BCS rate of 55% (Tarbox et al., 1992). What is most interesting about Tarbox's (1992) study is that 34% of the surgeons surveyed believed in equivalence between BCS and UM, but unintentionally presented bias towards UM, resulting in a UM rate of 60%. While these surgeons reported equivalence between the surgical options, they presented UM as the 'gold standard' inadvertently shaping patients' choice for UM (Tarbox et al., 1992).

Recent studies have demonstrated that some of the same surgeon factors which have been positively associated with the increased rates of BCS, are now associated with the increased rates of UM+/- CPM. Many of the studies documenting the increasing rates of UM+CPM have been conducted at academic centres (Arrington et al., 2009; Jones et al., 2009; Katipamula et al., 2009; King et al.,

2011; McGuire et al., 2009). A study conducted by Greenberg et al. (2011) examining institutional rates of BCS, and mastectomy (with or without reconstruction) across National Comprehensive Cancer Network (NCCN) sites demonstrated that mastectomy rates continue to vary across dedicated cancer centres, with 30-45% of women with ESBC undergoing mastectomy. A retrospective review examining predictors of mastectomy in a certified breast centre, reported that the primary predictor for a woman undergoing mastectomy was the surgeon (Reitsamer, Menzel, Glueck, Hitzl, & Peintinger, 2008). Even in this certified breast centre where the surgeons were dedicated breast surgeons, mastectomy rates for ESBC varied between 15.8 and 30.5% across surgeons (Reitsamer et al., 2008). Women who underwent surgery by those surgeons with a higher UM rate had twice the likelihood of undergoing mastectomy as compared to women who went to the lower UM performing surgeon (Reitsamer et al., 2008). Similarly, a study conducted by Arrington et al. (2009) demonstrated that women were 3 times more likely to undergo CPM if their surgeon was female. Despite these recent findings, it is not yet understood what role the surgeon might be playing in the decision-making experience of women with ESBC, particularly those who are now undergoing UM+/-CPM.

### 2.6.3 Surgeons' Recommendations

Surgeons' recommendations have also been described in the literature to impact the mastectomy rates. In an institute-wide retrospective review of all breast cancer cases conducted between 1990 and 1991 patients reported that the surgeon was the primary source of information for their surgical options (Kotwall et al., 1996). Kotwall et al. (1996) also reported that of the 89% of women who were recommended UM 93% complied, and of the 11% who were recommended BCS 89% complied. In a state-wide survey conducted by Katz et al. (2001) 57% of ESBC patients reported they received a treatment recommendation, of which 92% underwent the recommended treatment. Although these women were aware of the choice between BCT and UM, the vast majority underwent the procedure recommended by their surgeon (Katz et al., 2001). Another study examining those factors influencing women's treatment choice for ESBC reported that the surgeon's recommendation was the 2<sup>nd</sup> most influential factor in women's choice for surgery (Cyran et al., 2001). Of those women who received a treatment recommendation 93% underwent the recommended surgery, this was true for both BCT and UM (Cyran et al., 2001). More recent studies have not only demonstrated a similar effect with regards to surgical recommendations for BCS, they

have also described the effect on surgical choice when a physician recommendation is not put forth. An institutional study in Norway demonstrated that when BCT was recommended 86% of patient underwent this procedure (with 14% preferring UM), however when no recommendation was put 34% of patients underwent UM (Schroen et al., 2005). Similarly, a multi-institutional study in Hong Kong demonstrated a more striking response to a lack of recommendation. While 77% of women underwent BCT when it was recommended, only 37% choose BCT when it was left entirely to patient choice (Lam, Fielding, Ho, Chan, & Or, 2005). Despite these being institutional studies conducted outside of North America, two nation-wide SEER studies demonstrated a similar phenomenon. A study by Katz et al. (2005a) reported 30% of women with ESBC underwent UM, of which only 21.9% received a recommendation to undergo UM by their surgeon, the remaining 78.1% did not receive a recommendation and chose UM. Similarly, Morrow et al. reported in their SEER study that 98% of patients underwent BCT (2% opted for UM) when recommended by the surgeon, whereas 35.8% underwent UM when no recommendation was put forth (Morrow et al., 2009). Interestingly, it is not only the surgeon's recommendation that has been reported to impact the patient's surgical choice but also the patient's perception of their surgeon's preference, a phenomenon which has been described by both Hokanson et al. (2000) and Molenaar et al. (2004). Hokanson et al. (2000) described that many patients believed their surgeon made a strong recommendation towards either UM or BCT (even when no recommendation was made), and most complied with the perceived recommendation. In addition, patients reported that it was the (perceived) surgeon's recommendation that was the most influential factor in patients undergoing mastectomy (Hokanson et al., 2000). In light of the increasing rates of UM and UM+CPM it has not yet been examined what role the surgeon, and surgical recommendations might play in this changing trend.

## 2.7 The role of the patient

### 2.7.1 Clinicopathological and Demographic Factors

A number of clinicopathological and demographic factors have also been positively correlated with the increasing rates of both UM and UM+CPM. Numerous studies have demonstrated that tumour factors including tumour histology, tumour size, the presence of positive lymph nodes, and cancer stage (which is calculated from both size and lymph nodes) are independent risk factors for



unilateral mastectomy (Dragun et al., 2012a; Katipamula et al., 2009; Mahmood et al., 2013; McGuire et al., 2009). Tumours between 2-5cm increased the likelihood of UM by 1.4-2.6 times and tumours greater than 5cm have been reported to increase the likelihood of mastectomy by 9.1 times (Dragun et al., 2012a; McGuire et al., 2009). Similarly, the presence of mobile axillary level 1 and/or 2 lymph nodes has been reported to increase the likelihood of UM by 2 times (Mahmood et al., 2013; McGuire et al., 2009). While impacted by both tumour size and lymph node status, stage of disease has also demonstrated a positive correlation with UM. Both state and institute studies reported that stage 1 disease increased the likelihood of UM by 1.7 times and stage 2 disease increased the likelihood of UM by 1.3-2.8 times compared to women with DCIS (Dragun et al., 2012a; McGuire et al., 2009). Similarly, positive nodal disease, larger tumour size and higher tumour stage have all been positively correlated with women undergoing UM+CPM (Arrington et al., 2009; Dragun et al., 2012b; Stucky et al., 2010; Tuttle et al., 2007; Yao et al., 2010). An institute wide study reported an increased likelihood of women undergoing UM+CPM by 1.7 times when the index cancer was between 2-5cm, and 8.9 times when the index cancer was greater than 5cm (Arrington et al., 2009). Another institute based study demonstrated that with each additional increase in tumour size by 1cm, the likelihood of women undergoing UM+CPM increased by 1.4 times (Stucky et al., 2010). Nationwide and institute studies reported that the presence of positive lymph nodes increased the likelihood of undergoing UM+CPM by 1.2-1.7 times (Stucky et al., 2010; Tuttle et al., 2007). Two nationwide studies demonstrated that stage 1 cancers increased the likelihood of women undergoing UM+CPM between 0.77-1.3 times and stage 2 cancers increased this likelihood between 0.72-2.15 times (Dragun et al., 2012b; Yao et al., 2010).

Certain patient demographics have also been positively associated with the increasing rates of both UM and UM+CPM, these include: younger age, white race, higher socioeconomic status (SES), and higher education (Arrington et al., 2009; Dragun et al., 2012b; Gomez et al., 2010; Jones et al., 2009; Kurian et al., 2014; Mahmood et al., 2013; McGuire et al., 2009; Soran et al., 2013; Stucky et al., 2010; Tuttle et al., 2007; Yao et al., 2010). The increase in mastectomy rates have been most notable in women less than 50 years of age, this has been reported for both UM and UM+CPM (Arrington et al., 2009; Dragun et al., 2012b; Gomez et al., 2010; Mahmood et al., 2013; McGuire et al., 2009; Soran et al., 2013; Tuttle et al., 2007; Yao et al., 2010). Both institute and nationwide analysis have demonstrated that for each decade of age increased above 50 the likelihood of undergoing UM

decreases anywhere from 2-6 times until 80 years of age (Mahmood et al., 2013; McGuire et al., 2009). Institute, state and nationwide studies have also demonstrated that the likelihood of undergoing UM+CPM decreased from 2-9 times as women aged beyond 50 (Arrington et al., 2009; Dragun et al., 2012b; Yao et al., 2010). The age that has been most strongly associated with UM+CPM is 40-49, with women less than 50 years of age having a 2.2 times likelihood of undergoing UM+CPM rather than UM (King et al., 2011; Kurian et al., 2014; Tuttle et al., 2007; Yao et al., 2010). Similarly, white race has frequently been positively associated with the increased rates of UM+CPM, with a U.S. nationwide study reporting that 47% of women who chose UM+CPM were white (Hawley et al., 2014). Nationwide and statewide studies have also demonstrated that in comparison to women who identify themselves as non-Hispanic white, other races and ethnicities are less likely to undergo UM+CPM anywhere from 0.4-0.7 times (Kurian et al., 2014; Yao et al., 2010). In addition, one nationwide study demonstrated that in comparison to women who identify themselves as black, white women were 2.7 times more likely to undergo UM+CPM (Tuttle et al., 2007).

While age and ethnicity have been the most frequently reported demographic factors in relation to the increasing use of mastectomy, levels of education and income have also been positively associated with the increasing rates. Recent nation and statewide studies have demonstrated that the use of UM+CPM is highest in women with higher SES status. The likelihood of undergoing UM+CPM is 1.4 times higher than undergoing BCT for women in the highest SES class (Hawley et al., 2014; Kurian et al., 2014; Soran et al., 2013). Similarly, women with a college education or higher, more frequently underwent UM+CPM (Hawley et al., 2014; Jones et al., 2009; Yao et al., 2010). Recent NCCN institute studies have demonstrated that 72% -79% of women who underwent UM+CPM were college educated or higher (Jones et al., 2009; Soran et al., 2013).

While positive clinicopathological and demographic relationships have been demonstrated with the increase in both UM and UM+CPM such factors are unable to entirely account for the increasing rates, as such women with stage 1 or 2 disease, with or without positive lymph nodes, remain suitable candidates for BCT. The literature has suggested that despite such positive correlations for many women undergoing mastectomy, particularly UM+CPM, much of the surgical decision-making is dependent upon patient preference.

## 2.7.2 Patient Preferences

While little is known about the role of patients' choices and preferences in light of the increasing rates of mastectomy, the role of patient choice in surgical decision-making for ESBC has been previously described in the literature around the choice for BCS and UM when BCS was first introduced. As described in section 2.6.2 many patients undergo the surgical procedure recommended by the surgeon, however some women have chosen to undergo UM despite their surgeons having recommended BCT (Kotwall et al., 1996; Lam et al., 2005; Schroen et al., 2005). Additionally, there is a group of women who have chosen UM in the absence of a recommendation, suggesting that patient preferences may be influential in choice for surgery (Morrow et al., 2009). A survey conducted by Nold et al. (2000) examining women's treatment of ESBC with BCT, UM or UM with reconstruction (UM+R), demonstrated that the surgeon's recommendation was the most influential factor in those patients who decided to undergo BCS. In contrast, those patients who underwent UM or UM+R, reported the surgeon was of minimal influence in their decision-making (Nold et al., 2000). Rather, those patients who chose UM (with or without reconstruction) reported their fear of breast cancer was that which was most influential in the decision to undergo mastectomy (Nold et al., 2000). Similarly, a study conducted by Temple et al. (2006) found that key predictors to receiving BCS were the surgeon, and the contribution of the surgeon to the decision-making process. In contrast, the strongest predictor for UM was independent of the surgeon, rather it was the patients' concerns about recurrence (Temple et al., 2006). As described above, a statewide study conducted by Cyran et al. (2001) also demonstrated that the surgeon's recommendation was influential in women's decision-making. However, the most influential factor in those women who chose UM was fear of recurrence, with 61% of women who chose UM citing that as the reason for their treatment choice (Cyran et al., 2001). In contrast, women who chose BCS cited cosmesis as the most influential reason for their choice (Cyran et al., 2001). Such studies suggest that both perceived risk, as well as treatment-related values, can be influential in the decision-making process.

### 2.7.2.1 *Perceived Risk*

Early literature of breast cancer risk assessment has demonstrated that women frequently misperceive their risk associated with breast cancer, this is true for both the likelihood of being diagnosed with breast cancer as well as a recurrence and mortality associated with a breast cancer

diagnosis (Alexander, Ross, Sumner, Nease Jr., & Littenberg, 1996; Buxton et al., 2003; Evans, Burnell, Hopwood, & Howell, 1993). An institute survey demonstrated that only 11% of women correctly estimated the population lifetime risk of breast cancer, with 47% over-estimating the risk (Evans et al., 1993). In addition, 26% of women could not provide a personal lifetime risk (as they were unable to separate individual risk from population risk), and only 44% of women were correct within 50% of their actual risk estimate (Evans et al., 1993). Both institute and provincial studies have demonstrated between 75%- 91% of women overestimated their risk of breast cancer, with 50-71% estimating it to be at least 3 times higher than actual risk (Alexander et al., 1996; Buxton et al., 2003; Smith et al., 1996). Such overestimations occurred even in women with no family history of breast cancer (Smith et al., 1996). In addition an institute study demonstrated that of women who were receiving treatment for breast cancer, only 18% correctly estimated the likelihood of achieving a cure, with many interpreting their cancer as non-curative (Gattellari, Butow, Dunn, & MacLeod, 1999).

More recent literature has demonstrated those factors which might influence this overestimation of risk. A statewide study suggested that women who were younger, with a previous family history of cancer, and had more frequent exposure to health-media more often overestimated their risk (Haas et al., 2005). Another statewide study examined both patients own risk estimates for developing breast cancer as well as patients' responses when presented with their calculated risk estimates (Scherer et al., 2013). It was found that 48% of women misperceived their own risk, additionally 19% of women disagreed with their calculated risk estimates (Scherer et al., 2013). Of those women who disagreed with the estimates provided, 85% felt that the calculation failed to account for relevant personal information including family history, medical history and lifestyle (despite a thorough history being taken as part of the risk estimate process) (Scherer et al., 2013). Of note, 37% explicitly indicated that they felt their family history made them more likely to develop breast cancer than the estimate suggested (Scherer et al., 2013).

An additional concept that is closely linked to breast cancer risk estimates is the likelihood of developing a second (contralateral cancer). An institute study conducted by Abbott et al. (2011) reported that non-high risk women with a diagnosis of breast cancer estimated their risk of a CBC to be 31%, comparable to the risk of known high-risk breast cancer (BRCA positive) categories. In

addition, women estimated their risk of developing a local recurrence as 38.6% and metastatic disease as 26.2% (Abbott et al., 2011).

### ***2.7.2.2 Treatment Values***

Treatment-related values are those aspects of the treatment options which women might consider in their decision-making process, this includes the known advantages and disadvantage of each potential treatment, and may be influenced by a patient's perceived risk. In women undergoing decision-making for ESBC, the surgical advantages and disadvantages of BCT and mastectomy are weighted in accordance with that which the patient deems the most important and in-keeping with personal values. As described in Peirce's (1993) cognitive paper exploring decision-making in breast cancer, participants reframe treatment advantages and disadvantages within the context of their own personal preferences and understandings. Previous literature has demonstrated that those patients who have opted for BCT frequently voiced concerns around body image, cosmesis, sexual quality of life and partner intimacy (Benedict et al., 2001; Collins et al., 2009; Margolis, Goodman, Rubin, & Pajac, 1989; Temple et al., 2006). An institute-wide survey reported that those women who preferred to keep their breast were 5 times more likely to undergo BCT rather than UM, in contrast women who wished to avoid radiation were 6 times more likely to undergo UM, thereby demonstrating the role of personal preferences (Sepucha, Ozanne, Silvia, Partridge, & Mulley Jr, 2007). Multiple studies have reported that those women who have opted for UM rather than BCS expressed fear around cancer/recurrence, the need for subsequent surgery and radiation side effects (Benedict et al., 2001; Collins et al., 2009; Kirby, Manimaran, & Basit, 2008; Lam et al., 2005; Schou, Ekeberg, Ruland, & Karesen, 2002; Sepucha et al., 2007). Lam's study expands upon the understanding of women's treatment related beliefs for ESBC. Not unlike other studies, women who chose UM in Lam's (2005) study cited concerns around survival as the reason for choosing UM. However, Lam (2005) also reports that women incorrectly perceived BCT as less efficacious therefore, when given a choice the majority of women chose UM rather than BCT. A statewide SEER study reported that patients' concerns about benefits and risks were important to patients' decision-making (Katz et al., 2001). However it was also demonstrated that knowledge about such risks and benefits was low, with only 20% of women correctly responding that the risk of recurrence is similar across treatment options and only 36% correctly responding that rates of survival are the same with both BCT and UM (Katz et al., 2001). In addition, the role of treatment values in decision-making was

demonstrated by women indicating that ‘getting rid of disease’ was an important factors in the choice for UM; resulting in an increased likelihood of undergoing UM by 2.6 times (Katz et al., 2001). Limited patient knowledge in patients about the surgical risks and benefits has also been demonstrated in a more recent U.S. nationwide study (Fagerlin et al., 2006). Only 16% of women were able to correctly described slight differences in recurrence between UM and BCS and only 48% were aware of the equivalent survival across these treatment options (Fagerlin et al., 2006). Interestingly, a more recent study of unaffected women undergoing mammography screening demonstrated that the majority (73.3%) of patients would choose BCT if diagnosed with ESBC (Budden, Hayes, Pierce, & Buettner, 2007). However, the reasons that women indicated for choosing BCT were the same as those which have been reported elsewhere for choosing UM including, reducing recurrence, increasing length of life, potential for cure, removal all of the cancer, and providing ‘peace of mind’ (Budden et al., 2007). This suggests, as demonstrated by Pierce (1993), that the described surgical advantages and disadvantages are reframed through patients’ understanding and personal appeal.

In light of the increasing rates of mastectomy recent studies have examined those treatment values which have been associated with women who are now choosing UM. Multiple institute studies have demonstrated that despite the increase in rates of UM the reasons reported by women are unchanged, and include the desire to reduce the risk of recurrence and improved survival, with 45-71% of women citing such reasons (Ballinger et al., 2008; Fisher et al., 2012; Han et al., 2011). In addition a small proportion of women (32%) also voiced the desire to avoid radiation (Fisher et al., 2012). Sivell et al. (2013) used a cognitive framework to examine decision-making in ESBC and the authors found that it was treatment-related beliefs, that being the surgery which was seen as ‘right for them’, which was most strongly related with treatment choice rather than information received or the surgeons’ preference.

Given the recent increase in rates of UM+CPM there has been interest in that which might be shaping women’s preferences for more extensive surgery. Much like those women who chose UM, many women who have chosen UM+CPM report that their greatest concern is recurrence of their cancer (Beesley et al., 2013; Hawley et al., 2014; Howard-McNatt, Schroll, Hurt, & Levine, 2011; Rosenberg et al., 2013; Stefanek, Enger, Benkendorf, Flamm Honig, & Lerman, 1999). While it has

not been well described how a family history might shape personal preferences, multiple studies have demonstrated that having a positive family history of breast cancer has also been positively correlated with the rates of UM+CPM (Chung et al., 2012; Hawley et al., 2014; Howard-McNatt et al., 2011; Stefanek et al., 1999). While a family history may place a women into the high-risk category (and in-turn shape the choice for UM+CPM), it has also been demonstrated that despite women receiving a negative result after testing for the BRCA gene 37% of women still chose UM+CPM (Howard-McNatt et al., 2011). Genetic testing, with either negative or positive results, was an independent risk factor for the choice of UM+CPM. (Hawley et al., 2014; Howard-McNatt et al., 2011). Additionally, a U.S. nationwide study demonstrated that approximately 70% of women who chose UM+CPM did not have any substantial genetic or familial risk factors, thereby placing them in a non-high-risk category (Hawley et al., 2014). Another factor which might shape patients' preferences for UM+CPM is the role of reconstruction. As described above in section 2.5.2 rates of reconstruction have also been positively associated with the rates of UM+CPM, while it has not been well described, the role of cosmesis may in-part influence patients' preferences for mastectomy.

### 2.7.3 Patient Decision-Making Styles

In addition to patient treatment preferences, patient decision-making styles have also been positively correlated with the increased rates of both UM and UM+CPM. While Pierce was the first to describe such decision-making styles, Degner et al. (1997) demonstrated these styles in the setting of surgical decision-making for breast cancer. In a large prospective trial patients identified themselves as either active, collaborative, or passive decision-makers (Degner et al., 1997). The passive decision-maker prefers that the doctor makes the decision after considering the patient's opinion, or the decision is left entirely to the doctor (Degner et al., 1997). Passive decision-makers readily accept the physician's advice regarding surgical treatment of choice and often do not seek additional information (Degner et al., 1997; Pierce, 1993). In contrast, the active decision-makers prefer to make their own treatment decisions, or prefer to make the final decision about treatment after considering the doctor's opinion (Degner et al., 1997). The active decision-maker often seeks out multiple sources of information including medical and non-medical opinions, and combines the information and advice they have gained with the need to balance their own treatment values (Degner et al., 1997; Pierce, 1993). The active decision-maker considers the final decision to be her own and it may or may not be in keeping with that recommended by the physician (Degner et al.,

1997). The collaborative decision-maker lies between the active and the passive decision-makers. Collaborative patients consider the advice of their support system, their own concerns and in-turn balance these with the advice obtained from the physician (Pierce, 1993). The final decision is then a shared responsibility between the patient and her physician (Degner et al., 1997).

Women who are now undergoing mastectomy have frequently been described to be active decision-makers, thereby *choosing* to undergo UM+/-CPM. Three nationwide SEER studies documented that women who received UM rather than BCS more frequently reported themselves as active decision-makers (Hawley et al., 2009; Katz et al., 2005a; Lantz et al., 2005). In one study of those women who reported making the decision alone (without consideration for their surgeon's opinion) 66% underwent either UM or UM with reconstruction (Lantz et al., 2005). Another of the studies reported 30% of women having undergone UM rather than BCS (Katz et al., 2005a). Of these women, 41% made the decision alone and 37% made the decision with their surgeon after expressing their own preference for mastectomy (Katz et al., 2005a). These women also reported higher levels of concern around recurrence and radiation than those women who underwent BCS (Katz et al., 2005a). A similar trend has also been demonstrated among ethnic minority women in the U.S., with 17% of Latina women undergoing UM (Hawley et al., 2009). 34% of these women stated it was solely their choice and 38% having chosen it after considering the surgeon's recommendations (Hawley et al., 2009). This phenomenon has also been described in multi-institute studies in the UK. Caldon et al. (2008) described 26% of women who were suitable candidates for BCT undergoing UM. Of those who underwent mastectomy 83% described themselves as active decision-makers, whereas only 58% of women who chose BCT did so (Caldon et al., 2008). In addition, when examining centres which perform a high number of mastectomies in comparison to low-volume centers, Caldon (2011) reported that surgeons at high-volume centres less often put forth a treatment recommendation and more often the patients made the decision without the physician. A large multi-institutional study of those women who choose UM+CPM have also identified those women as active decision-makers (Nekhlyudov et al., 2005). Of women who chose UM+CPM, 45% made the decision alone and 37% made the decision after considering their doctor's opinion (Nekhlyudov et al., 2005). Only 15% of women reported sharing the decision for UM+CPM with their physician and just 3% of women reported their doctor made the decision (Nekhlyudov et al., 2005). Interestingly, a qualitative study examining the decision-making experiences of women with breast cancer described that most active



decision-makers often contemplated their treatment options even before their initial surgical consultation (Lally, 2009), suggesting the role of sources of information beyond the surgical consultation.

#### 2.7.4 Sources of Information

Patients' use of additional sources of information (beyond that which is provided by the surgeon and/or the health care team) has been described in breast cancer decision-making since BCT was first introduced as a treatment option. Examination of the early breast cancer literature highlights the role that family and friends in the decision-making process (Valanis & Rumpler, 1985). Studies describing women's decision-making for BCT and UM have reported that patients turn to a number of sources of information, these include: the surgeon, spouse, other physicians, children, friends, breast cancer support groups, media, the internet and cancer societies (Benedict et al., 2001; Halkett, Arbon, Scutter, & Borg, 2005; Smitt & Heltzel, 1997; Ward, Heidrich, & Wolberg, 1989). A multi-institute study reported that approximately 50% of women involved their spouse in their decision-making process (Benedict et al., 2001). Additionally 20-25% of women turned to friends and between 23-27% of women sought out the advice of other women with breast cancer during their decision-making process, irrespective of whether women ultimately underwent BCT or UM (Benedict et al., 2001). In addition, a study conducted by Valanis and Rumpler (1982) examining healthy women's treatment preferences demonstrated that more than 57% of women would choose BCT if diagnosed with ESBC; many of which did so based on a friend's previous successful experience with lumpectomy. A similar study conducted by Ward et al. (1989) in the ESBC population demonstrated that both women who underwent UM and those who underwent BCT reported other women's experiences (both positive and negative) as influential in their surgical choice. Additionally, both groups ranked family and friends as important sources of information after their surgeon (Ward et al., 1989).

The role of non-physician sources of information have not been well described in the setting of increasing mastectomy rates, particularly the decision-making process for UM+CPM. However, in an institute based retrospective study women reported that the decision to undergo UM+CPM was influenced by their spouse/partner's suggestions in 68% of women and friends/family's suggestions in 64% of women (Soran et al., 2013). In addition, 49% of women reported their partner's opinion

influenced their decision and 30% of women reported that a friend or family member influenced their decision of UM+CPM (Soran et al., 2013).

## 2.8 Study Rationale

While patients' treatment-related preferences, decision-making styles, and risk perceptions have been reported to vary with regards to the surgery chosen, some of the same factors have been associated with all surgical options. For instance, peace of mind, likelihood of cure, and being an active decision-maker have all been positively associated with UM, UM+CPM and BCS. It is not understood how patient's preferences, decision-making styles and sources of information might shape a patient's surgical choice. Similarly, it is not understood what role the surgeon and treatment-related factors (such as MRI and reconstruction) play in women undergoing UM+/-CPM. Surgical decision-making for breast cancer is a complex process, one which is filled with both uncertainty and seen of urgency for breast cancer patients. A myriad of information has the potential to effect the irreversible decision which must be made between multiple treatment options during an emotionally charged time. It is not known to what extent previously described factors are currently influencing surgical decision-making for early-stage breast cancer. Furthermore, it has not been addressed whether there are new, unexplored factors which may be influencing the surgical rates. Studies have demonstrated that undergoing UM+/-CPM does not result in better survival but it has been associated with more post-operative complications. In addition, it has also been demonstrated that more surgery has greater potential for both psychological as well as physical long-term concerns. Therefore, understanding the surgical decision-making process for ESBC is important in developing strategies to improve our ability to discuss issues of importance to women, and to facilitate informed decision-making.

## 2.9 Study Objectives and Questions

**The intent of this study was to explore the decision-making process for those women with unilateral ESBC who are undergoing UM+/-CPM for their treatment.** A holistic understanding of the decision-making experience will help to characterize the experiences and events which were meaningful to women in their decision-making processes. Within this primary objective are secondary objectives:

- to gain an understanding of what a diagnosis of ESBC meant for the women in this study
- to appreciate women's experiences from the time of their diagnosis until the time of their surgery
- to explore those factors that might be influential in women undergoing UM+/-CPM for their surgical treatment.

These objectives give rise to the principle question in this study:

*Why are non-high risk women with unilateral early-stage breast cancer now undergoing unilateral mastectomy and/or contralateral prophylactic mastectomy for treatment of their breast cancer?*

This question will be addressed through the secondary questions:

- What meaning do women attribute to their diagnosis of early-stage breast cancer?
- What experiences and events are meaningful to women during their journey of breast cancer from the time of their diagnosis until surgery?
- What role do patient preferences play in women undergoing UM+/-CPM as treatment for ESBC?
- What role does the surgeon play in surgical decision-making process and the increasing rates of mastectomy?
- Are treatment-related factors such as MRI, radiation and reconstruction influential in women's decision-making?
- Are there other, not yet explored, factors which are influential in women who are undergoing UM+/-CPM for ESBC?
- How do women's experiences, meanings, preferences, in addition to the surgeons', the health-care environment (and perhaps other, not yet known factors) translate into women undergoing mastectomy(ies) for treatment of ESBC?

## Chapter 3 – Methodology

### 3.1 Overview

This project is a grounded theory study which involved three phases: semi-structured interviews with patients, semi-structured interviews with two populations of surgeons and triangulation of the patient and surgeon interviews. The 29 patient interviews were conducted with women in the local urban community who had undergone either UM or UM+CPM for surgical management of their ESBC. The surgeon interviews yielded two datasets, 22 Ontario-based surgeons and 23 U.S.-based surgeons who shared their experiences about the surgical consultation and perspectives on the increasing mastectomy rates. These data sets were compared and contrasted producing a deeper understanding of the role the medical environment plays in the choice for mastectomy. The patient interviews, Ontario surgeon, and U.S. surgeon interviews were then triangulated, developing a richer understanding of those beliefs that shape treatment decision-making resulting in the choice for mastectomy.

This chapter presents the rationale for a qualitative study design, the theoretical underpinnings and methodological framework of the study, a description of the research team, a detailed description of the study design and methods, a discussion on rigour, a section on reflexivity and a discussion on ethical considerations.

### 3.2 Rationale for a qualitative study design

Qualitative research is a method of inquiry which develops an understanding of a given phenomenon through the discovery of meaningful patterns attributed to the phenomenon by those individuals involved (Auerbach & Silverstein, 2003). In contrast to quantitative research which measures relationships, qualitative research stresses the socially constructed nature of reality, that being, the meaning that people bring to events and gain from experiences (Denzin & Lincoln, 2005).

Qualitative research locates the research participants within their world, employing interpretive practices that make this world visible, thereby interpreting a phenomenon through the meaning that people bring to it (Denzin & Lincoln, 2005).

A qualitative approach was chosen for this study for two reasons. Firstly, there are no qualitative studies conducted to-date that have explored the factors surrounding the recent increase in mastectomy rates in non-high risk women. While the recent increase in rates of both UM and UM+CPM for treatment of ESBC have been well documented in quantitative literature, the reasons underlying these recent changes in mastectomy rates remain unclear. While many quantitative studies have identified those demographic and pathological factors which have been associated with the increase in mastectomy, quantitative research is unable to delineate *why* some women who could undergo BCS ultimately undergo UM+/-CPM. A qualitative study moves the understanding of the phenomenon of increasing mastectomy rates beyond the positive correlations identified through quantitative studies. A qualitative study design is well suited to develop an understanding of the meaning women attribute to a breast cancer diagnosis, the current setting for surgical decision-making, women's experiences in their decision-making process for ESBC, and those factors and experiences which are influential in women's decision-making process resulting in the choice for UM+/-CPM. As the choice for mastectomy does not result in improved survival or decreased sequelae, it is important that the health-care community understands the experiences and factors of importance to women electing to undergo mastectomy, so these considerations may be included in the decision-making process.

Secondly, a qualitative study will not only elucidate the meaning that women give to their diagnosis and their decision-making process, but it also allows for exploration of the patient-physician decision-making dyad and the meanings that each member brings to this relationship. While substantial literature has been reported around the patient-physician relationship, there has been very little description of this relationship when patients opt to undergo treatment discordant from medical guidelines. Exploring this relationship will provide an understanding of this dyad within the phenomenon of increasing mastectomy rates. Gaining an understanding of the patient-physician relationship from the subjective experiences of both patients and surgeons will result in a rich understanding of the interactions between the individuals and the decision-making environment.

### 3.3 Theoretical Underpinnings: Social Constructivism

Prior to undertaking any research project the researcher must identify their positionality, that being, who the researcher is in relation to the 'other' (where the other refers to both those individuals

within the research project, as well as those within the larger world), and the paradigm (worldview) the researcher holds with respect to knowledge production (England, 1994; Merriam et al., 2001). The principle investigator's positionality with regards to those relationships, both in and beyond the research project, is further described in section 3.5 below. The paradigm held by the primary investigator and that with which this study was conducted was a constructivist paradigm.

Paradigms are worldviews that reflect a belief system about what reality is (ontology) and the nature of knowledge (i.e., the way one gains knowledge about that reality (epistemology)) (Guba & Lincoln, 2005). A researcher's ontological and epistemological viewpoint guide the research by providing a lens through which the research process is undertaken (Guba & Lincoln, 2005; Weaver & Olson, 2006). Constructivist ontology accepts that there are multiple realities, which are socially constructed and experientially based; knowledge is therefore relative, and constructed through meanings and understandings which are socially developed (Guba & Lincoln, 2005). Unlike the positivist paradigm, constructivism does not attend to the belief that there is one universal objective truth, nor is there a single, ideal way to ascertain that truth. Rather than attempting to uncover a single truth, epistemologically, the constructivist paradigm implies that understanding of a phenomenon is relative and realities are emergent and co-constructed through relationships between the researcher, the participants and their surroundings (Weaver & Olson, 2006). While reality is dependent on the intersubjective construction, there may be elements of reality that are shared across groups whose experiences lie within similar social constructions (Guba & Lincoln, 2005).

Social constructionism is a suitable theoretical framework to explore this research question as social constructionism proposes that subjective and social meanings are created through social relationships (Poerksen, 2004). As human beings are active agents, social meanings emerge through actions, and in-turn influence (re)actions, creating social processes (Charmaz, 2009; Poerksen, 2004; Weaver & Olson, 2006). These processes can be explored and understood through relationships and actions, thereby allowing for the understanding and theorization of social processes, such as surgical decision-making (Charmaz, 2009; Poerksen, 2004; Weaver & Olson, 2006). Social constructionism allowed this research question to be explored through the meanings and experiences of those involved in the decision-making process. As in keeping with the constructivist paradigm, to attain a rich, in-depth understanding of those experiences that were impactful in the decision-making

process, it was first necessary appreciate the social meanings constructed by the participants involved in this phenomenon of changing surgical trends. Research was conducted with an emphasis on language, meaning and action, focusing on the decision-making process as it occurred at the subjective and social level. Conducting this research through a constructivist paradigm allowed an empathetic understanding of the participant's meanings given to words and actions; this resulted in a rich account of the phenomenon rather than a mere description of the events. Exploring the meaning our participants had given to breast cancer diagnosis, the experiences throughout the decision-making process, and the larger socio-cultural relationships allowed for a relative understanding of the decision-making process and theorization of those factors which result in women undergoing mastectomy.

### 3.4 Methodological Framework: Grounded Theory

#### 3.4.1 Tenets of Grounded Theory

Grounded theory (GT) methodology arose out of Glaser and Strauss' attempts to derive social theories from observable actions, and is therefore particularly suited to research areas where one is attempting to understand a social process or change (Charmaz, 2000; Holloway & Wheeler, 2010). The tenets of GT include: simultaneous data collection and analysis, constructing codes from data analysis, and the constant comparison of the evolving categories (Charmaz, 2000, 2009; Dey, 2000; Glaser & Strauss, 1967; Strauss & Corbin, 1990). Memo-writing, the process of writing down thoughts and ideas as analysis progresses, is an essential component of grounded theory. It increases reflexivity (described below), and serves to assist with the interpretation of the evolving codes (further described in data analysis below) (Charmaz, 2000, 2009; Strauss & Corbin, 1990). Through the comparison and contrast of evolving concepts and emerging categories, gaps within the data are identified (Charmaz, 2009). Theory development is then advanced through subsequent focused sampling (theoretical sampling), data collection and analysis, driving the research toward theory construction (Charmaz, 2000, 2009; Dey, 2000). The evolution of grounded theory has resulted in the development of a systematic yet adaptable approach to data collection and analysis which culminate in the constructing of a theory grounded in the original data (Charmaz, 2000; Dey, 2000; Heath & Cowley, 2004; McCann & Clarke, 2002). Rather than a set of strict rules, grounded theory methodology serves as a guideline to approach the data in a unique way which results in early

analysis, directing focused data collection (Charmaz, 2009; Strauss & Corbin, 1990). The very data collected and analyzed serve to form the foundation of the developing theory.

### 3.4.2 Approaches to Grounded Theory

Since its inception, GT methodology has existed on a paradigmatic spectrum with Glaserian GT occurring within the positivist/post-positivist paradigm, Charmazian GT falling within the constructivist paradigm and Strassian GT oscillating between a post-positivist/constructivist stance (Charmaz, 2009; Glaser & Strauss, 1967; Mills, Bonner, & Francis, 2006; Strauss & Corbin, 1990). While the tenets of GT remain the same across paradigms, the differences lie in how one goes about data collection, analysis and interpretation. Not only does grounded theory differ in paradigmatic orientations (thereby differing substantially in ontological and epistemological positions), this difference is reflected in the approach to data analysis and subsequent theory construction. Glaserian GT proposes that a thoughtful study design and thorough data collection can ‘*uncover emergent theory*’, with the implication that there is one truth within the data waiting to be uncovered by the researcher (Glaser & Strauss, 1967; Mills et al., 2006). In contrast, Strauss and Corbin (1994) acknowledge that there are elements of truth, but also multiple interpretations of that truth. Charmaz puts forth the notion that there are multiple realities and therefore multiple truths which exist, thus the theory developed from the data must be reflective of this richness, embedding the participants narratives within the data (Charmaz, 2009; Mills et al., 2006). Within the constructivist paradigm theory is defined as a relative understanding of the social process rather than a predictive explanation (as defined in a positivist framework) (Charmaz, 2009). As reality is dynamic and socially constructed, the theoretical understanding of a social processes are viewed as abstract and interpretive (Charmaz, 2009; Guba & Lincoln, 2005; Jeon, 2004). Therefore, the constructivist methodological approach serves as a way to learn about the world, proposing that as individuals interact with one another in a given context common patterns of behaviour emerge and define what is occurring within a given phenomenon, thereby providing a means for developing theories that present a reflection and understanding of the social processes in the world (Charmaz, 2000; Dey, 2000; Strauss & Corbin, 1990). As GT allows for the study of fundamental social processes within a social setting, this methodology is well situated within the constructivist paradigm. Grounded theory research results in the generation of conceptual understanding of a situation grounded in the data,



thereby offering insights and meaning to the actions observed (Charmaz, 2000, 2009; Mills et al., 2006). A completed grounded theory presents the studied process in terms of a theoretical narrative, describing the meanings, experiences, and interactions under which the studied phenomenon transpired (Charmaz, 2009; Dey, 2000; Heath & Cowley, 2004). Rather than analyzing social process through existing theories, the intent of a grounded theory study is to represent a social phenomenon through the generation of a substantive theory, that being, an in-depth understanding representative of the differences and similarities across the given phenomenon (Adelman, 2010; Auerbach & Silverstein, 2003).

A constructivist grounded theory methodology was used for this study as the intent was to explore and present a conceptual understanding of a social phenomenon (surgical decision-making) from the meaning given to the phenomenon by those experiencing it. The principle investigator wished to explore the decision for mastectomy from the viewpoint of those patients and surgeons involved in decision-making process, understanding the meaning and experiences occurring within this social phenomenon, generating a theoretical narrative of surgical decision-making process representative of those involved. The resultant substantive theory presents an understanding of the decision-making processes in-terms of those individuals experiencing this phenomenon, demonstrating the meanings and events influential in the choice for mastectomy. The aim of a grounded theory study is to explain a social phenomenon through the generation of a substantive theory ‘grounded’ in the original data (Charmaz, 2009; Dey, 2000; Strauss & Corbin, 1990); the substantive theory represented through this research illuminates those experiences shaping the decision-making process.

### 3.5 Research Team

At the time of commencement of this thesis the principle investigator was a physician and had completed the primary and secondary year of general surgery residency, a discipline that is responsible for the surgical management of breast cancer. Prior to having completed medical school the principle investigator has completed an honors degree bachelor of science in physiology; previous research included a 4<sup>th</sup> year research project examining neonatal physiology and a needs assessment of street youth shelters in developing nations. The impetus for this project rose out of the principle investigator’s clinical training in general surgery. It was the clinical experience of having

delivered the news of cancer diagnoses, and the conversations that followed, which generated an interest in the decision-making experiences of women during this vulnerable time. During the developmental stages of this thesis a notable amount of quantitative literature was being published in medical journals describing the increasing mastectomy rates. After reflecting upon both clinical experiences and discussions with local leaders in this field, this thesis, a qualitative study exploring the factors influencing changing rates, was undertaken. Having never completed qualitative research prior to beginning the PhD a number of courses, as well as guidance from supervisors, committee members and other researchers within the field, helped the principle investigator gain the necessary skills to complete this thesis.

There were three other members who consisted of the research team. Two thesis supervisors brought very different yet complimentary skills and perspectives to the project. While both are general surgeons who are cross-appointed in clinical epidemiology, one is a breast surgeon and the other is a colorectal surgeon. While one supervisor's clinical focus is colorectal cancer, this supervisor's research interest is in long-term survivorship issues for cancer patients, cancer screening effectiveness, and quality of surgical care. Specifically, she has examined patterns of care in ductal carcinoma in-situ and the use of breast self-exam. She also holds a chair in the provincial cancer health services research program and serves on the guidelines committee for the largest international clinical oncology society. The other supervisor has extensive experience with the management of breast cancer both clinically and through her research. Her research expertise is in qualitative research, with an emphasis on grounded-theory methodology. Her current work includes management and treatment of breast cancer and understanding the complex environments in which health professionals and patients make decisions through examining the use of multidisciplinary cancer conferences, and surgical standards documents. The other research member is an associate researcher and cross-appointed in the faculty of nursing. She has extensive experience in qualitative research particularly in the area of cancer patients and survivors. Her research has included examining young women's experiences with breast cancer with an emphasis on improvements in their cancer care.

## 3.6 Study Design

### 3.6.1 Overview

This project was a grounded theory study which had 3 phases and consisted of 3 different data sets. The first phase consisted of interviews with women who had undergone either UM or UM+CPM (with or without reconstruction) for treatment of their ESBC. This phase was designed to gain an understanding of the meaning that women attributed to their breast cancer diagnosis and explore women's journeys from the time of their diagnosis until their surgery, in order to develop a rich understanding of those experiences that were influential in women's decision-making. The second phase consisted of two sets of interviews. The first set of interviews was with Ontario-based surgeons. These interviews were designed to gain an understanding of the surgeons' experiences with the current surgical management for ESBC, including the changing rates of mastectomy, as well as their role in these changing rates. In keeping with grounded theory methodology, constant comparative analysis of these interviews suggested that the experiences of the Ontario surgeons may differ from the quantitative findings which have been published in the literature. Notably, there appeared to be less of a role between individuals and the medical practice environment than suggested by the quantitative literature. To gain a more in-depth understanding of these findings (in keeping with theoretical sampling), interviews with surgeons from the United States, including those centres which had published quantitative literature, were conducted generating a third data set. Given the differences in the health-care practice environments, comparing and contrasting the Ontario and U.S. surgeon interviews allowed for a greater understanding of the role that the medical milieu plays in shaping the decision-making experiences. The third phase of the study consisted of triangulation of the 3 datasets from phase one and phase two. Triangulation of these data sets resulted in a rich, in-depth exploration of the decision-making experiences of women choosing mastectomy. Understanding the meaning women attributed to their breast cancer diagnosis, their experiences with cancer, the health-care team and the larger sociocultural environment, and the roles each played in women's decision-making, was reminiscent of the Health-Belief Model (a known theoretical framework in medical decision-making, further described in chapter 6 and 7). The Health-Belief Model (HBM) was applied to the concepts and categories of the individual data sets, resulting in a rich, in-depth understanding of the phenomenon of the increasing choice for mastectomy in the setting of ESBC and theoretical expansion of the HBM.

### 3.6.2 Sampling

Sampling in qualitative research is guided by the ability of the participants to communicate their experiences of the phenomenon of interest (Auerbach & Silverstein, 2003). Within qualitative research different approaches to sampling exist. The approach used is guided both by the research methodology as well as the nature of the research question. Grounded theory calls for the researcher to employ theoretical sampling that is, sampling to elaborate and further refine emerging categories (Charmaz, 2009). However, initial sampling cannot be guided by theoretical sampling (as no evolving categories/theories exist), rather initial sampling is purposive and participants are selected based on having both undergone the phenomenon of interest and to reflect the diversity within a given population (Barbour, 2001; Coyne, 1997). Within this study both purposive and theoretical sampling were used, with purposive sampling for initial sampling and theoretical sampling used to further explore evolving categories. In addition, snowball sampling was employed as a strategy to reach initially inaccessible populations (this is further described below) (Auerbach & Silverstein, 2003).

#### Phase I- Patient Participants

Initial access to patients was facilitated by key informants (surgeons who treat breast cancer) who were known to the research team. Five surgeons from five different hospitals in the Greater Toronto Area (GTA) provided access to their patient databases for the purposes of recruitment. Selection of these five hospitals was based on purposive sampling. Quantitative literature suggested that the phenomenon of increasing mastectomy rates was most predominant in designated cancer hospitals and academic teaching centres (Arrington et al., 2009; Greenberg et al., 2011; Katipamula et al., 2009; King et al., 2011; McGuire et al., 2009). To explore the phenomenon of increasing mastectomy rates and gain an understanding of how the location of treatment might shape women's experiences, both academic and non-academic centres were included in this study. Patients were then purposively sampled from 3 academic centres (2 of which were designated cancer centres and 1 which has a designated breast screening centre but is not a comprehensive cancer centre) and 2 non-academic centres. As both distance to radiation facilities as well as access to a reconstructive surgeons have been reported to impact women's surgical choice (Ashfaq et al., 2014; Boscoe et al., 2011; Habermann et al., 2014; Jacobs et al., 2008; Nattinger et al., 2001) the centres were limited to

the GTA, where access is not restricted to neither reconstruction nor radiation, thereby removing these as external factors which might influence women's surgical choice.

As the intent of the first phase of the study was to gain a rich, in-depth understanding of women's resultant choice for mastectomy, participants were selected to reflect the diversity within the GTA patient population that have undergone mastectomy in recent years. Specifically, women had undergone either UM or UM+CPM within the previous 9-12 months from the date of interview were identified from the surgeons' databases. Chart review was then conducted to ensure that participants had ESBC, were at average risk for developing a contralateral cancer and suitable candidates for BCT. Participants were varied in age and ethnicity to reflect the GTA population of women with breast cancer. In addition, patients' marital, socio-economic, and education background were documented at the time of the interview. Women were invited to participate in this study if:

- They were English speaking and felt comfortable conducting an interview in English
- Voluntarily agreed to participate in the study
- Had been diagnosed with early invasive (stage I or II) breast cancer and were suitable candidates for BCT but underwent UM within the previous 9-12 months of the time of the interview
  - Suitability for BCT was defined as having no absolute contraindications or relative contraindications to undergoing either lumpectomy or radiation therapy, as defined by the NCCN guidelines (National Comprehensive Cancer Network, 2014c). Absolute contraindications included radiation therapy during pregnancy, diffuse suspicious or malignant micro-calcifications, widespread diffuse disease that cannot be achieved by local incision through a single incision that achieves negative margins, and T4 non-inflammatory breast cancer without complete skin resolution after undergoing neoadjuvant chemotherapy. Relative contraindications include prior radiation therapy to the chest wall, active connective tissue disease of the skin, tumors >5cm, women with known genetic predisposition. Both absolute and relative contraindications were listed as exclusion factors for the study. Chart review including medical history, clinical notes and imaging was completed for each potential participant to ensure they did not meet the exclusion criteria
- Women with early invasive (stage I or II) breast cancer who were not at high-risk of contralateral breast cancer and underwent UM+ CPM within the previous 9-12 months of the time of the interview

- High-risk was defined according to the NCCN guidelines(National Comprehensive Cancer Network, 2014b), women are at increased risk for developing a contralateral breast cancer if they had a known genetic mutation including BRCA1/2, P53 or PTEN, had a previous history of chest wall radiation, a previous personal history of ovarian cancer, or were diagnosed with breast cancer at less than 35 years of age. Women with a diagnosis of unilateral breast cancer might also be at increased risk if they have a known genetic mutation within their family, have two relatives (first or second degree) on the same side of the family with breast and/or pancreatic cancer, have a first or second degree relative with ovarian cancer, have one family member with both breast and pancreatic/thyroid/sarcoma/endometrial cancer/lymphoma /gastric cancer, or a first degree relative diagnosed with breast cancer less than 45 years of age.
- Women who have undergone CPM and are known BRCA positive carriers or have a significant family history where thereby excluded from participating in this study
- Women who are less than 35 yrs of age may be at increased risk for increased recurrence; some literature suggests this select group should preferentially undergo UM and were therefore excluded from this study (Kromen et al., 2000; Touboul et al., 1999)
- Women who had undergone surgery greater than 1 year or less than 9 months were excluded as the intent was to interview women while the decision-making process was in the recent past, but not while they were undergoing active treatment as to minimize the potential for negative emotional sequel that might potentially occur from recalling the events associated with receiving a diagnosis of breast cancer. Such concerns are further discussed in section 3.10 Ethical Considerations.

The intent was to interview 2-3 participants from each surgical category (UM or UM+CPM) from each surgical center.

### Phase 2- Surgeon Interviews

Initial access to **Ontario surgeons** was achieved through the Canadian Medical Directory, a publically available annual directory which lists physicians according to their provincial location and clinical area of practice. In addition, the Canadian Medical Directory provides physician practice information including year of medical school graduation, location of medical practice, and subspecialty training. Surgeons were purposively sampled to ensure they varied in location of practice (academic and community), length of practice, extent of training (subspecialty training or no

subspecialty training), and gender. As the intent of this phase of the study was to explore the surgeon's experiences with management of ESBC, understand the meaning they attribute to women's choice for mastectomy and explore their interactions with women in the decision-making process, those surgeon attributes which had been previously cited in the literature to influence mastectomy rates (length of practice, extent of training, location of practice and gender) were varied through purposively sampling (Arrington et al., 2009; Chapgar et al., 2006; King et al., 2011; Reitsamer et al., 2008).

With the **United States surgeons** the initial sampling was facilitated by the research team. Key informants were purposively sampled. Suggestions for subsequent interview participants (snowball sampling) were taken from the initially selected key informants. Of the surgeons suggested, purposive sampling was again employed to ensure the participants varied in the aforementioned attributes.

Both Ontario and U.S. surgeons were invited to participate in this study if :

- They were English speaking and felt comfortable conducting an interview in English
- Voluntarily agreed to participate in the study
- Had completed general surgery residency
- Practiced independently for at least five years
- Were still in active practice
- Currently perform surgery for the treatment of ESBC
- Did not subspecialize in a field unrelated to breast cancer.

The intent was to interview 2-3 participants from of the aforementioned categories within each population while ensuring equal numbers of male and female surgeons from each population.

Purposive and snowball sampling (as described above) were strategies used to accomplish theoretical sampling, that is, sampling reflecting the evolving data collection and analysis, ensuring that the researcher 'maximizes opportunities to compare events, incidents and happenings' (Strauss & Corbin, 1990). As data analysis progresses and categories emerge, through the constant

comparative process theoretical sampling is employed to clarify, expand upon, or gain a deeper understanding of the emerging categories (Charmaz, 2009). As theoretical sampling is a concurrent and ongoing process with data collection and data analysis the extent of sampling cannot be pre-determined but rather is only determined by the emerging theory/ understanding of the phenomenon of interest (Coyne, 1997). Theoretical sampling was employed in this study until repetition and confirmation of evolving categories (theoretical saturation) was achieved. Theoretical saturation is achieved when no new categories emerge from the data, each category is fully developed with no new data emerging within categories, and no new theoretical insights are achieved (Charmaz, 2009; Guest, 2006).

### 3.6.3 Data Collection

Prior to the commencement of data collection Research Ethics Approval was obtained from each of the five hospitals from which patients were sampled and from the University of Toronto.

Data for all three data sets was completed using semi-structured interviews. Patient interviews were conducted in person while surgeon interviews were conducted over the phone.

Open-ended interviewing is considered the mainstay of data collection in qualitative research, being considered a directed ‘ conversation with a purpose’, facilitating an in-depth exploration of the phenomenon of interest with those individuals who have had relevant experiences (Charmaz, 2009; Loflanad & Lofland, 1995). The intent of the open-ended interview is to gather an in-depth representation of the individual’s experiences and the meanings attached to these experiences, thereby gathering an understanding of the phenomenon from the participant’s view, resulting in rich detailed material for analysis (Charmaz, 2009; McCann & Clarke, 2002). The semi-structured interviews consisted of open-ended questions reflecting on the participants’ experiences, thereby allowing participants to emphasize the aspects of their experiences which are most meaningful (Holstein & Gubrium, 1995). As the intent of this study was to understand the decision-making processes from those individuals who have experienced the phenomenon of interest, allowing for their interpretation, semi-structured interviews provided a detailed exploration of the phenomenon resulting in rich detailed data (Charmaz, 2009; Duffy, Ferguson, & Watson, 2004; Holstein & Gubrium, 1995; McCann & Clarke, 2002).



The interviews conducted in this study were semi-structured consisting of open-ended questions which are loosely structured around the topic of interest (Britten, 1995). In this study the interviews began with a few broad open-ended questions, this helped to both establish a rapport between the interviewer (AMC) and the participants, as well allowed unanticipated statements and stories to emerge (Glaser & Strauss, 1967). Within grounded theory methodology the use of broad questions early-on in the data collection process is important as it allows the participant to define their world, experiences, and attributed meanings, thereby facilitating the introduction of new ideas and perspectives (Glaser & Strauss, 1967). While semi-structured interviews consists of a set of open-ended questions with the use of prompts to guide the participant, they still allow flexibility allowing both the researcher to pursue new ideas or issues of importance introduced by the participant, as well as the opportunity for the participant to share the phenomenon through his/her experiences (Rose, 1994). As data collection proceeds, the range of interview topics may narrow that which specifically advances the developing theory; however, the researcher must guard against forcing interview responses, or placing the responses into preconceived categories (this potential for ‘forcing data’ is further discussed below under reflexivity). Similar to the advancement of an evolving theory through theoretical sampling, through concurrent data analysis, the interview questions may be refined to enrich developing concepts. As data collection and analysis progresses the questions become more focused and reflective of the evolving categories, in-turn the interviews are guided by conceptual gaps that exist in the emerging theory (Charmaz, 2009; Duffy et al., 2004).

The interviewer plays an active role in the interview process; a role which has been criticized in positivist approaches, suggesting introduction of researcher bias into the study (Auerbach & Silverstein, 2003; Duffy et al., 2004). However, the active role of the interviewer is very much in keeping with the epistemology of social constructivism as reality is subjective and socially constructed, with the researcher and the participant both involved in knowledge production (Charmaz, 2000; Holstein & Gubrium, 1995; Jeon, 2004). The interview process is not a simple recount of a previous event, rather it is the construction of a new event. Within the constructivist paradigm the researcher is part of the world they study, the participant’s meanings and views are constructed through their social experiences and expressed to the researcher through the interview process (Charmaz, 2009; Holloway & Wheeler, 2010; Jeon, 2004). The interview provides an account of the experience from a certain perspective with a specific purpose. The interview process

is interactive, resulting in a reflection of both what the participant and the interviewer bring to the interview and the relationship they construct (Charmaz, 2009; Jeon, 2004).

### **3.6.3.1 .Phase 1- Patients**

This phase was designed to explore the meaning women attributed to a diagnosis of EBSC, women's experiences from their time of diagnosis until their time of surgery and the decision-making processes that occurred during this time period. Exploring women's experiences with the decision-making process resulting in mastectomy included: women's discussion of EBSC and the meaning attributed to the disease, whether women appreciated a 'choice' in treatment options, the discussion around treatment options, and those factors influential in the decision-making process. To gain an understanding of the women's experiences semi-structured interviews were conducted. Prior to completing an interview each potential participant was contacted via a mail-out letter of invitation (Appendix A) which introduced the study as well as contained a response form (indicating or declining interest in the study) (Appendix B) a postage-paid envelope as well as a copy of the consent form (Appendix C). Positive response letters, as well as non-responders, were followed up with a phone call describing the study, answering questions, and scheduling an interview if the participants agreed. The consent form was included in the mail-out package for review prior to the interview process, however consent was obtained in-person prior to the start of the interview. Participants were assured that their responses would be anonymized and remain confidential.

#### *Interview Guide Development:*

A semi-structured interview guide (Appendix D) was developed based on the literature review (Chapter 2) completed to gain an understanding of what has been explored to date with regards to surgical management for EBSC, as well as to identify potential gaps in the literature. The concepts explored included: understanding of the disease process and treatment modalities, cosmesis, risk perception, treatment preferences, role of the support system, role of the surgeon, role of health-care providers, the decision-making style of the patient, and the role of external resources. The questions were framed within a constructivist framework, with emphasis on exploring the participant's views, experienced events and actions. This list was not intended to be exhaustive, rather the interview process was intended to be free-flowing and the guide only served as a prompt to the interviewer to ensure all areas of decision-making were explored, were they not readily volunteered by the

participant. As the study was exploratory, it was felt that there may be factors which were influential in a women's decision-making that had not been previously documented. Therefore, the pilot guide was also reflective of this need to explore beyond what was previously known, and allow for the experiences of the participants to emerge through the interview process.

This guide was piloted with 4 patients, 2 who underwent UM and 2 who underwent UM+CPM. The interviews were audio-recorded; upon completion they were transcribed verbatim, analyzed and reviewed by the entire research team. Review of the pilot interviews revealed a rich description of the patient's experience with their decision-making processes. Through open-ended questioning minimal use of the prompts were required. Discussion of the transcripts between the principle investigator and 2 members of the research team resulted in improvements of the interview technique and minor modifications of the interview guide to ensure non-directive, open-ended questioning. While the process of transcription can alter the data collected, the content of the transcribed interviews were confirmed against the original audio recordings; accuracy of the transcribed content was >95%.

#### *Interviews:*

One-on-one interviews were conducted in-person in a quiet, private room at the patient's medical institution or a location of the patient's choice. The interviews were conducted between Sept 2010-Oct 2011 and lasted between 50-91 minutes. The interviews were audio-taped as this allows for greatest accuracy and allows the interviewer to establish and maintain eye contact and thus develop rapport with the interviewee (Holstein & Gubrium, 1995). Overall reflections, difficulties during the interviews, and non-verbal cues were noted after completion of the interview. The principle investigator (AMC) conducted all interviews to maintain consistency (Auerbach & Silverstein, 2003).

While an interview guide was used, the interview questions were open-ended and the prompts were only used should the topic have not been readily introduced by the participant. In addition, the order of the questions on interview guide was not intentionally followed. While all interviews started with very open-ended broad questions, the natural flow of the interview unfolded, as led by the participant. This allowed the responses to be expressed through the participants' own experiences and framework, rather than forcing participants to work within the framework of the interviewer

(Auerbach & Silverstein, 2003; Dey, 2000; Silverman, 2000). Questions from the interview guide were directly addressed later in the interview had they not been shared during the earlier free-flowing participant volunteered discussion.

### **3.6.3.2 Phase 2: Surgeons**

This phase was designed to explore the surgeons' role in surgical decision-making for ESBC, their experiences with women who ultimately undergo mastectomy, their perceptions on the increasing mastectomy rates, their interactions with the health-care environment, and the meaning they attribute to mastectomy. To gain an understanding of the surgeons' experiences semi-structured interviews were conducted. Prior to completing an interview each potential Ontario-based surgeon participant was contacted via a mail out letter of invitation (Appendix E ) which introduced the study as well as contained a response form (indicating or declining interest in the study) (Appendix B) a postage-paid envelop as well as a copy of the consent form (Appendix F). Potential U.S.-based participants were contacted via an email letter of invitation (Appendix G) which introduced the study as well as a copy of the formal letter of invitation (Appendix E) and consent form (Appendix F). Both Ontario and U.S. positive responders, as well as non-responders, were followed up with a phone call describing the study, answering questions, and scheduling an interview if the participants agreed. The consent form was included in the initial mail-out/email package for review prior to the interview process, however consent was obtained verbally prior to the start of the interview. Participants were assured that their responses would be anonymized and remain confidential.

#### *Interview Guide Development:*

Similar to patient interview guide a semi-structured interview guide (Appendix H) was developed for the surgeon interviews. The guide was based on the literature review (Chapter 2) completed to gain an understanding of what has been explored to date with regards to surgical management for ESBC, as well as to identify potential gaps in the literature. The concepts explored included: understanding of the disease process and treatment options, approaches to patient education, use of MRI, reconstruction and radiation, decision-making styles and the patient-physician relationship. Again, this list was not intended to be exhaustive, rather the interview process was intended to be free-flowing and the guide only served as a prompt to the interviewer to ensure all areas of decision-making were explored, should they not be readily volunteered by the participant. The pilot guide was

also reflective of this need to explore beyond what was previously known, and allow for the experiences of the participants to emerge through the interview process.

This guide was piloted with 4 surgeons, 2 who were from academic facilities and 2 from non-academic facilities. The interviews were audio-recorded; upon completion they were transcribed verbatim, analyzed and reviewed by the entire research team. Review of the pilot interviews revealed a rich description of the surgical consultation, reflecting the experiences and opinions of the surgeons. Through the open-ended questioning minimal use of the prompts were required.

Discussion of the transcripts between the principle investigator and 2 members of the research team resulted in improvements of the interview technique and minor modifications of the interview guide to ensure unbiased, open-ended questions. While the process of transcription can alter the data collected, the content of the transcribed interviews were confirmed against the original audio recordings; accuracy of the transcribed content was >95%.

#### *Interviews:*

One-on-one interviews were conducted over the phone at a time that was convenient for the surgeon participants. Ontario-based interviews were conducted between February – October 2012 and US-based interviews were conducted between January – May 2013. Interviews lasted between 26 and 93 minutes. The interviews were digitally recorded as this allows for greatest accuracy (Holstein & Gubrium, 1995). Overall reflections, difficulties during the interviews, and non-verbal cues were noted after completion of the interview. The principle investigator conducted all interviews to maintain consistency (Auerbach & Silverstein, 2003).

It is known in the literature, and was confirmed by previous team member's research experience, that busy professionals prefer not to be interviewed during work hours as this interrupts their day and decreases the quality of the interview (Burnard, 1994). Due to the nature of the surgeon's schedule this can result in interviewing at the extremes of the day, which is better suited to telephone rather than in-person interview. Furthermore, as interviews were conducted both across Ontario and across the U.S. it was easier to achieve data collection via telephone interviews and a reasonable use of both human and economic resources (Musselwhite, Cuff, McGregor, & King, 2007). It has been argued that telephone interviews do not have visual cues, and therefore lose some of the richness of the interview. However research comparing face-to-face and telephone interviews found no difference in length of interview, quality of answers, or the richness of the analysis (Musselwhite et

al., 2007; Sturges & Hanrahan, 2004). While there are no visual cues in telephone interviews, Sturges (2004) illustrated that both interviewee and interviewer use, and attend to, audio cues more readily.

While an interview guide was used, the interview questions were open-ended and the prompts were only used should the topic had not been readily introduced by the participant. In addition, the questions on interview guide were intentionally not followed in order. While all interviews started with very open-ended broad questions, the interview was allowed to flow naturally, as led by the participant. This allowed the responses to be expressed through the participants' own experiences and framework, rather than forcing participants to work within the framework of the interviewer (Auerbach & Silverstein, 2003; Dey, 2000; Silverman, 2000). Questions from the interview guide were directly addressed later in the interview had they not been shared during the earlier free-flowing participant volunteered discussion.

### 3.6.4 Data Analysis

Data analysis in grounded theory can be thought of as three discrete processes: description, categorization and theorization. These processes occurs through stages of analysis known as: initial (also known as open coding), focused (also referred to as selective coding by Glaser), axial and theoretical coding (also referred to as selective coding by Strauss) (Charmaz, 2009; Glaser & Strauss, 1967; Strauss & Corbin, 1990). As this study was conducted with a constructivist paradigm Charmaz's language will be used when describing data analysis, that being, initial, focused, axial and theoretical coding. Initial coding is the descriptive process and results in the generation of codes (ideas), while focused and axial coding are the categorization process and result in the generation of concepts and categories, and theoretical coding is the theorization process resulting in theory generation or expansion. Coding is the fundamental analytical process by which data is broken down into discrete parts, conceptualized, interpreted and re-assimilated into a theoretical understanding of the phenomenon of interest (Charmaz, 2009; McCann & Clarke, 2002; Strauss & Corbin, 1990).

While described in a liner fashion coding does not actually occur in this manner, rather analysis within grounded theory occurs through what is known as the *constant comparative method*. Constant

comparison is a reiterative, inductive process comparing each piece of data against every other piece of data (Boieje, 2002; Glaser & Strauss, 1967). Data collection and data analysis are a concurrent process; as analysis progresses and categories evolve newly gathered data undergo coding, and subsequently comparison with concepts and categories (Charmaz, 2009; Strauss & Corbin, 1990). As analysis progresses the original data is returned to and re-examined within the context of developing concepts and categories (Glaser & Strauss, 1967). Evolving data analysis shapes data collection (such as seen with theoretical sampling, and modification of the interview guide as described above), thereby directing the researcher towards a focused exploration of emerging themes, and ultimately moving toward the development of theory (Charmaz, 2009; Jeon, 2004). The cyclic comparison of ‘old’ and ‘new’ data is repeated until new data does not bring forth any new codes, nor enriches the evolving categories (*saturation*) (Boieje, 2002). Once saturation is reached, new data is easily assigned to one of the already existent categories and does not further lend to the evolving theory. Constant comparative analysis will result in the development of a theoretical framework, grounded in the original data (Walker & Myrick, 2006).

The analytical coding process of description, conceptualization, categorization and theorization has been specifically adopted in the study using Charmaz’s coding framework (Charmaz, 2009).

#### *Initial Coding:*

Initial coding is the first level of data analysis; it is the process of breaking down, and categorizing the original data (Charmaz, 2000, 2009; Strauss & Corbin, 1990). The process is inductive and the codes are derived from the data itself, and as described by Charmaz (2009) they are provisional (in that they will evolve and change through constant comparative analysis), comparative and grounded in the data. As outlined by Charmaz (2009), initial codes in this study were derived directly from the data, rather than having predefined or developing categories applied to the data. Also in keeping with the constant comparative methods, these codes transformed and evolved throughout the analysis process. Initial coding was completed independently by two investigators (the principle investigator and one supervisor). In this initial stage data were coded in multiple ways to ensure all ideas within the data were uncovered (Charmaz, 2009). Coding of the interviews occurred via line-by-line reading of the transcriptions and identification of repeating ideas. The individual data were

grouped into similar codes representing the ideas shared by the study participants, therefore the developing codes remained grounded in the meaning and language attributed to them by the study participants. However, initial coding is not simply a mechanical process. Rather breaking down the data and assigning labels requires the researcher to interpret the data as ideas, defining their meanings, recognizing the researcher's assumptions and stimulating thoughts (Charmaz, 2000, 2009; Coffey & Atkinson, 1996). As coding continued to occur there was constant comparison between these evolving concepts, comparing data with data developed richer more thorough codes, and identified gaps within the codes. At any stage during the analysis it was possible to return to the original data for further refinement or enrichment of the developing themes (Charmaz, 2000, 2009; Strauss & Corbin, 1990). The initial coding process was completed only when no new codes were emerging from the data and the principle investigator saw the possibility of an emerging theory.

#### *Focused Coding:*

Charmaz's (2009) focused coding allows the researcher to complete a more directed analysis of the data than that which is completed during initial coding. Focused coding asks the research to examine and discern the most noteworthy and frequent codes generated through initial coding, allowing for a richer analysis and further generation of meaning (Charmaz, 2009). Using these codes, the initial data are re-approached, combining initial codes into larger concepts. However, focused coding is neither a linear nor mechanical process (Charmaz, 2009). Moving from initial codes into larger concepts requires that the researcher ask how the data 'fit', which may require returning to the original data and re-examining the initial codes (Coffey & Atkinson, 1996). However, the researcher must be certain not to 'force' the initial codes into the developing concept; those which seem to be a poor fit may represent a yet unexplored gap in the data. Diverging or poorly 'fitting' data can be addressed through reflexive memoing (see study rigor below), and by returning to the original data, as well as further data collection.

#### *Axial Coding:*

Axial coding is a higher-level coding which reassembles the disassembled data (through initial coding) into central categories (Charmaz, 2009; Strauss & Corbin, 1990). The intent of axial coding



is to synthesize and reconstruct the data in a new manner (categories), with the data holding new relationships to one another, thereby forming new insights and understanding (Charmaz, 2009; Coffey & Atkinson, 1996). Within axial coding the dimensions and definitions of the categories become clarified, and relationships between categories develop (Charmaz, 2000, 2009; Dey, 2000). Within this study categories were formed from grouping those concepts which had become evident through focused coding, into mutually exclusive categories. Axial coding allowed for the comparison and contrast of emerging categories. Analyzing the developing categories within the context of one another formed larger connections across the data. Resultant categories were used to guide theoretical sampling and compared against subsequently collected data (Strauss & Corbin, 1990). The process of axial coding continued until there were no new categories, nor enrichment of categories from ongoing data collection.

### *Theoretical Coding*

Theoretical coding is the highest level of coding and is done with the intent of reconstructing the data as a meaningful whole. Theoretical coding continues to build upon those relationships that were developed between categories during axial coding. Within theoretical coding categories are further collapsed into overarching themes, of which a core code (theme) is acknowledged. This core theme acts as fulcrum around which other categories and themes can be brought together in a coherent and explanatory fashion (Charmaz, 2000). Integration of the categories occurs at an abstract level with the goal of constructing a theory which explains most of the variation in the data while accounts for the relationships between the categories, and has implications for known or related theories (McCann & Clarke, 2002; Strauss & Corbin, 1990; Walker & Myrick, 2006). Within constructivist grounded theory, a final theory need not be a unifying statement of relationships between empirical observations, but rather a set of well-developed concepts related to one another which results in a framework of understanding of the studied phenomenon (Charmaz, 2009). While this understanding may have multiple realities and indeterminacies, it serves to describe how individuals construct meaning to their events, and how such meaning shapes actions; thereby presenting a substantive theory grounded in the original data, allowing for an understanding of the phenomenon of interest (Charmaz, 2000, 2009; Jeon, 2004; Strauss & Corbin, 1990).

All interviews were transcribed verbatim, anonymized and underwent coding as outlined by Charmaz's grounded theory method. Two researchers (the principle investigator and one of the supervisors) independently completed initial, focused and axial coding. During this process, repeating ideas and key concepts were individually extracted from the data. As described above this process was first completed for the pilot interviews (patients, Ontario physicians and U.S. physicians) prior to subsequent data collection. Three researchers (the two who completed initial and open coding, in addition to a third researcher) met routinely to discuss the evolving codes, including any challenges or discrepancies in the coding process. During such discussions the context or meaning of a code was examined and/or the original text was returned to achieve consensus of evolving categories and dominant themes. As described below in section 3.8 the use of multiple investigators in completing independent coding increases the range of meanings and perspectives brought to the data, thereby minimizing the chances that important concepts go unseen (Auerbach & Silverstein, 2003). As the data underwent constant comparative analysis, data collection and analysis occurred concurrently within each phase of the study. Initial coding was completed using line-by-line analysis which occurred on the transcripts themselves. As coding progressed through focused and axial coding excel spreadsheets were used to organize the evolving concepts and categories, their developing meanings, and representative quotes. As new concepts and categories (and their respective meanings) developed through the iterative process, they were added to the spreadsheet and compared with the analysis of all other interview transcripts. Repeating concepts were reviewed by the principle investigator and assembled into related categories. Similarly, categories were examined and relationships between categories were elicited. Within each phase of the research study a core theme was identified. The third phase of the research study also underwent focused and axial coding; rather than initial coding of the interview transcripts, the data sources were the codes generated in phase 1 and phase 2. As put forth by a concept known as triangulation (further described below) these codes underwent iterative analysis thereby refining and expanding upon the developing categories. Within theoretical coding categories were expressed in relation to one another and their ability to explain the phenomenon of increasing mastectomy rates. Examination of these categories resonated with the known theoretical model, the Health-Belief Model. During the final stage of theoretical coding the relevant literature pertaining to the Health-Belief Model was sought out. Iteratively examining the concepts of the Health-Belief Model to the developed categories,

further refined these categories and the relationships between the categories thereby forming the basis of a substantive theory (an enrichment and application of the Health-Belief Model).

### 3.7 Triangulation

Triangulation is defined as a multi-method approach to data collection and analysis. The argument underpinning the use of triangulation is that a phenomenon is best understood when approached from a combination of research methods (Given, 2008). Triangulation has been described as ‘a strategy that allows researchers to identify, explore and understand different dimensions of the unit of study, thereby strengthening their findings and enriching their interpretations’ (Given, 2008). Using multiple methods to approach a given research question can result in a more inclusive and thorough representation of the phenomenon being studied, which in-turn may allow a deeper theoretical understanding of the phenomenon and/or theory generation. Thus, the use of triangulation is well in-keeping with research conducted within a constructivist paradigm.

There are five approaches to triangulation: data, researcher, methods, theory and data analysis (Denzin, 1989; Kimchi, 1991). Data triangulation refers to the use of two or more data sources to investigate the same research question, this includes: varying data sources over the time in which they were collected, the location in which they were collected, and/or multiple research populations (Begley, 1996; Denzin, 1989; Farmer, Robinson, Elliott, & Eyles, 2006). The use of multiple data sources attending to the same phenomenon allows the researcher to approach the given phenomenon through multiple dimensions, each representing a slightly different experience and contributing to a more holistic representation of the phenomenon (Farmer et al., 2006). The use of multiple data sources may also illustrate dissonant findings which, rather than serving as a contradiction, allow for a more multi-faceted understanding of the phenomenon (Flick, 2007; Thurmond, 2001). Investigator triangulation refers to the use of two or more investigators undertaking a prominent role in either data collection and/or data analysis (Denzin, 1989). Although investigator triangulation is most often cited as a tool to minimize research bias, this thinking falls within the positivist paradigm (Kimchi, 1991; Thurmond, 2001). In contrast to positivist thinking, the inclusion of multiple researchers with varying expertise can lend itself to a constructivist approach to data synthesis. As independent researchers provide differing expertise, they will approach the data analysis and theorization with differing perspectives. The systematic comparison of the researchers’ influences on

the analysis process can lend itself to exploring different orientations to the data, thereby producing a richer and more thoughtful representation than could be provided from a single researcher alone (Flick, 1992; Halcomb & Andrew, 2005). Methodological triangulation was originally described as the use of two or more methods within a study (Denzin, 1989). Theoretical triangulation is undertaken when more than one theoretical lens (framework or paradigm) is applied to the data during data collection and/or data analysis. Data analysis triangulation refers to employing more than one data analysis technique to a given data set (Kimchi, 1991).

Triangulation was employed during two stages of this study. During the initial data collection and data analysis stage (Phase 1, Phase 2a and 2b) this study employed data and investigator triangulation. Additionally, during Phase 3 of this study data, investigator triangulation and data analysis were employed as a means of comparing and contrasting the concepts and categories developed in phase 1 and 2.

To develop a rich understanding of the phenomenon of increasing mastectomy rates purposive sampling ensured data sources varied over both research populations (patients and surgeons) and location. Specifically, this included patients who had undergone UM and those who had undergone UM+CPM as well as treating female and male surgeons who varied in length of training and practice. Location of the research populations was also varied to include women who had been treated at academic and community centres, and surgeons who practiced in Canadian and American surgical centres. As the intent of this grounded theory study, was to develop a theory that presents a rich understanding and is representative of the phenomenon, those involved in the surgical decision-making (patients and physicians) across a number of surgical centres were included in the purposive sampling. Investigator triangulation occurred during the data analysis phase of this study. While the principle investigator completed all of the data collection, 3 researchers participated in data analysis. Each researcher offered either differing methodological or clinical expertise to the data analysis process. During the initial coding the interviews were coded independently by two researchers. During axial and theoretical coding three researchers were involved. Each researcher contributed to the analytic discussion, providing varying perspectives from their previous research and clinical knowledge. A specific example arose when one of the senior researchers questioned the role of the family in the decision-making process, as this was a notable finding from a previous research study

in which she had been involved. Returning to the data it was then asked why the role of the family was not as well represented by our population and what role did family play, thereby enriching the understanding of this phenomenon by attending to a pertinent ‘negative’ finding.

The third phase of this study allowed for the comparison and contrast of the research findings from the first and second phase. This allowed for a more enriched understanding of the decision-making process and a more in-depth representation of the phenomenon of increasing mastectomy rates. Data analysis triangulation occurred by applying codes across data sources, as has been frequently illustrated in content analysis (Hsieh & Shannon, 2005). Using the codes and categories generated from the patient and surgeon interviews, data analysis triangulation was completed. As described by Farmer et al. (2006), given the multiple data sets and the desire to generate an integrated set of findings, convergence and dissonance of emergent ideas, concepts and categories was examined using the constant comparative method. Both similar and unique contributions to the research question were gained from coding of data across the data sets, thereby broadening the range of findings and expanding upon the understanding of the research phenomenon. While completing axial coding with these data sets the triangulated data was iteratively explored and refined into larger themes. As described for phase 1 and 2 multiple researchers were involved in this data analysis thereby employing investigator triangulation. Through constant comparative analysis and discussion among the research team it became apparent that the developing categories were reminiscent of aspects of the Health-Belief Model. Completing axial coding using the concepts of the Health-Belief Model, the triangulated data were iteratively explored and refined into larger themes driving the research toward theory construction. Theoretical coding resulted in theory generation which expands upon the Health-Belief Model, applying it to the understanding of the surgical decision-making process in ESBC.

### 3.8 Rigour

Study rigour is defined as the way one demonstrates integrity or trustworthiness of the research process (Rolfe, 2006; Tobin & Begley, 2004). Guba and Lincoln (Guba, 1981; Lincoln, 1995; Lincoln & Guba, 1985) put forth 4 criteria for assessing rigor of a qualitative study: credibility, dependability, transferability and confirmability. Within qualitative research there are multiple approaches which can be used to address rigour. The approaches used are dependent on

methodological and paradigmatic congruency and therefore depend on both the methodological and theoretical orientation of the research project. Ensuing rigour within a constructivist paradigm mandates that the research is reflective of the epistemological and ontological principles of constructivism, that being, the study represents the realities of the study participants, experiences, and meanings given to the research phenomenon (Sandelowski, 1993). A constructivist study also requires that the researcher attend to their position within the research process and the co-creation of meaning during the data collection process, this is further described in section 3.6 (reflexivity) below.

*Credibility* is thought of as ensuring the accuracy of the study. The intent of qualitative research is to describe the phenomenon of interest from the experience of those involved. Therefore, credibility attends to how ‘accurately’ the research findings represent a given phenomenon and the surrounding experiences (Marshall & Rossman, 2011). Credibility is addressed through the rigorousness of the methods of fieldwork, the trustworthiness of the researcher and the fundamental appreciation of qualitative inquiry and methods, reflected in purposeful sampling and holistic thinking (Marshall & Rossman, 2011). In this study the credibility of the methodology was maintained by remaining true to the tenets of grounded theory including theoretical sampling which was guided by the evolving theory, constant comparative analysis which allowed for a rich and thorough representation of the phenomenon, and memo-writing describing the thoughts and decisions of the principle investigator throughout data analysis. In addition, initial and focused coding was completed independently by both the principle investigator and one research supervisor. Axial and theoretical coding was completed by three individuals of the research team. This allowed not only for the substantiation of concepts which are being identified, but also for discussion surrounding coding discrepancies, as has been established in the literature (Charmaz, 2009; Rolfe, 2006; Strauss & Corbin, 1990).

Contradictory codes resulted in enriching the data collection process, asking the researchers to reflect upon their memo-writing (and thereby the definitions and decisions made around specific codes) and identify gaps within the evolving theory. This guided sampling and data collection in previously unforeseen directions.

*Dependability*, as defined by Guba (1981), is the replicability of the research study. Within a constructivist paradigm it would be argued that as reality is co-created through the researcher and

those involved in the research process, if repeated, the understanding and representation of a given a phenomenon would not result in identical results (Marshall & Rossman, 2011). Rather, dependability within a constructivist paradigm emphasizes the need for the researcher to account for the ever-changing context within which the research occurs (Shenton, 2004). Within this research project, dependability meant describing all decisions and formulating ideas throughout the entire length of the research process, from inception until write-up. Within this research project such decisions included but were not limited to the development and enrichment of codes as the coding process progressed, the participant population and changes which occurred as guided by theoretical sampling, and the research team's decisions and thoughts around the evolving theory development). As stressed by Lincoln and Guba (1985) there 'are close ties between credibility and dependability', many of the approaches undertaken to ensure credibility also ensure dependability with the difference lying in the appreciation of what methodological steps were taken (credibility) and why these steps were undertaken (dependability) (Shenton, 2004). In addition to memo-writing (described above) as an approach to achieving credibility, reflexivity (described below) is also fundamental to addressing the role of the researcher within the research project. Additionally, an audit trail was kept throughout the research process. An audit trail documents all decisions made throughout the research process. It incorporates both memos made throughout the coding process and reflexive journaling as well as documentation of any methodological decision-making such as sampling (both participants and locations). An audit trail not only serves to record all decision-making in the research process, it also allows an outsider to witness the analytical process, as data are compared and contrasted and ideas are explored (Wolf, 2003). All major decisions made during the study, whether inclusionary or exclusionary, were noted as well as the reasoning behind such decisions

*Transferability* is defined as the degree to which the findings from the research project can be transferred to other contexts or settings. A grounded theory study conducted within a constructivist paradigm maintains that the aim is to understand a social phenomenon through the experiences of those involved in this phenomenon, generating a substantive theory 'grounded' in the original data (Charmaz, 2009; Dey, 2000). While reality is dependent on the individuals who occupy this construction, there may be elements of reality that are shared across groups (Guba & Lincoln, 2005). Therefore, it can be argued that a GT substantive theory may present elements and themes

transferable across similar groups, allowing these research results to be informative across similar settings and beyond the immediate study group. However, it is also argued that given the contextual dependency of qualitative research, the responsibility of the research investigator lies in providing a rich thorough description of the research setting and participants thereby providing the knowledge allowing for potential transferability, rather than providing generalizable results to another (not yet contextually explored) population (Lincoln & Guba, 1985; Shenton, 2004). The research settings, participants, and research team within this study have all been described in depth, providing a thorough representation of the context in which the study was conducted and those involved in the research findings.

*Confirmability* is considered the representation of the research findings as the result of the experiences and ideas of the informants, rather than the characteristics and preferences of the researcher (Shenton, 2004). Triangulation is one such approach, allowing the representation of differing groups of participants across different settings, thereby more fully exploring the phenomenon of interest and limiting the presuppositions of the researchers (Shenton, 2004). In addition, a clear representation of whose voice was embodied in the analysis and where the voice of the researcher lies in the research findings is ascertained through both an audit-trail and reflexive journaling. This study employed triangulation, the use of an audit-trail and reflexive journaling to ensure confirmability.

## 3.9 Reflexivity

### 3.9.1 Approaches to Reflexivity

As this is a GT study within a constructivist paradigm, maintaining reflexivity is essential to create trustworthy data. Within the constructivist paradigm it is held that research knowledge is produced through interactions. Therefore the researcher generates knowledge through the interactions with the research participants. As knowledge is produced by the meaning given to interactions and experiences, both the researcher and the participant bring their individual assumptions and understandings to these interactions (Jeon, 2004). It is therefore necessary for the researcher to have a thorough familiarity of themselves (who they are both within the research process as well as the world in which they live) and the meanings given to situations (Cutcliff, 2000).



Reflexivity is the awareness the researcher has of themselves and the ways in which the research process has been shaped (Charmaz, 2009; Cutcliff, 2000; Lincoln & Guba, 1985). Within the constructivist paradigm the researcher is considered to be an inherent part of all aspects of the research process: from framing the research question, devising an approach to sampling, selecting a methodology, the data collection process, and data analysis including the ongoing understandings of the research phenomenon (Charmaz, 2009; Cutcliff, 2000; Jeon, 2004). Arguments made against involving the researcher's lived and intellectual knowledge in the research process is a positivist notion; one cannot simply set aside their knowledge and prior experiences (a process known as bracketing). Rather, reflexivity allows the researcher to identify themselves in this research process (Charmaz, 2009; Finlay, 2002). To be self-reflexive calls for the researcher to be transparent in their thinking process and questioning of assumptions made (Finlay, 2002). The epistemological and ontological assumptions of the researcher must be reflected throughout the entire research process and the methodology and methods of data collection must then be congruent with these assumptions (Arminio & Hultgren, 2002). Data analysis must reflect the voice of the researcher and the participants and the interactions constructed must manifest in the analysis (Arminio & Hultgren, 2002). Reflexive bracketing is an attempt to recognize the researcher's prior knowledge, assumptions and beliefs, and purposefully attend to these within theory construction (Ahern, 1999; Mantzoukas, 2005). While reflexivity (and reflexive bracketing) is essential in establishing trustworthiness in the research process it is in itself not a tangible technique. Rather, reflexivity is illustrated through other practices such as audit trails (described above) and reflexive journaling.

Reflexive journaling allows the researcher to keep an account of the decision-making processes during *the* research experience. It should highlight both insight into the ongoing research process as well as a personal reflection of the researcher within the research process (Holloway & Wheeler, 2010). Reflexive journaling includes information about decisions within the study; with the focus on the researcher's thoughts, insights, and ideas that are generated as the study progresses (Lincoln & Guba, 1985). Throughout this research study a journal was kept recording prior experiences within the breast cancer community, assumptions, and expectations of the data collected. As described above in section 3.5, the principle investigator was a physician in a general surgery residency program. This research question in-part was shaped by her clinical experience within her surgical training. The researcher also witnessed the impact of breast cancer through its effect on family

members and their experiences with the meaning attributed to a breast cancer diagnosis. Given the position of the health-care provider, as well as offering familial support, it was recognized that the researcher's perspective and "reality" of breast cancer may differ substantially from the participants in this study. This positionality was documented and attended to throughout the research process through reflexive journaling. The contents of the journal were used as an additional data source during the constant comparative process. Thereby allowing an interplay between the researcher's knowledge, beliefs and the emerging data, and in-turn sensitizing the researcher to emerging concepts, a process consistent with theory construction within constructivist grounded theory methodology (Charmaz, 2009; Lincoln & Guba, 1985; Turner, 1981). In addition, communication with the entire research team during data collection and analysis ensured that extracted concepts and evolving categories emerged from the data and not due to expectations held by the principle investigator.

Reflexive journaling also allowed the researcher to reflect upon the process of data collection and data analysis, paying particular attention to the interview process and ensuring the responses were not shaped by the expectations of the researcher. Failing to recognize the researcher's preconceptions and assumptions shapes both the questions asked as well as the answers received during the interview process, and could result in failing to explore the entirety of the phenomenon and meaning given to that phenomenon from the experiences of the participants (Duffy et al., 2004; Jeon, 2004). A participant response may be unintentionally shaped through either the emphasis placed onto the question or the manner in which the question is posed (Charmaz, 2009; Holstein & Gubrium, 1995). Failure to attend to personal assumptions and beliefs can result in the researcher failing to explore concepts fundamental to the development of the evolving theory (Charmaz, 2009; Duffy et al., 2004). Forcing the interview process could result in data which misdirects analysis and falsely shapes ongoing theory development and subsequent data collection, therefore it is necessary that the researcher be reflexive about the nature of their questions (Charmaz, 2009; Jeon, 2004). The interview questions must reflect the epistemological and ontological stance, endorse the methodology and be genuine to participants involved and the evolving theoretical construct. Open-ended questions allow the interviewer to obtain rich data while preventing preconceived ideas. Reflexive journaling, in addition to open-ended questions allow the response to be expressed through

the patient's experience and their own preconceptions rather than forcing them to work within the framework of the interviewer (Charmaz, 2009; Duffy et al., 2004; Holstein & Gubrium, 1995).

### 3.9.2 The Reflexive Process

I, as the principle investigator in this research project entered this project from the place of a surgical resident, having been embedded in the traditions of the 'scientific process' for the majority of my education and training to date. I was raised in the school of positivist or (at the most liberal) post-positivist thought. I learned early on in childhood about the scientific method. That being one begins the research project with a hypothesis and then seeks out data to then 'confirm' or 'refute' that hypothesis. This process thereby suggests that the hypothesis (while merely one person's viewpoint to a phenomenon) could then be validated through tools known to and utilized by the researcher. Of course, as I continued to develop and grow in my studies I learned that there was more than one way to approach a research question and that different 'tools' might elicit slightly different 'results', thereby identifying within post-positivist thinking.

My first exposure to constructivist thought was in my undergrad. Feminist studies challenged me to think beyond the 'dominant' messages, and to think about the world as 'another' might experience it. Suggesting that there is more than one reality to the same shared experience. However, this study was my first experience in completing research in a school of thought outside of the quantitative post-positivist paradigm. Having only ever approached a question through the quantitative framework, much of the initial undertaking of this research project required that I 'find' myself as a qualitative researcher. I needed to discern what I believed about the nature of reality and the construction of knowledge, and identify those assumptions that I carried with me from my post-positivist background. Early on in this project I spent much time trying to 'learn the language' of qualitative research. Immersing myself in coursework, readings, conversations with qualitative researchers/thinkers and discussions with other graduate students challenged me to continue to examine the assumptions I carried with me and my positionality. Many times during this research study I found myself oscillating between my post-positivist upbringing and my newly exposed constructivist thinking. Many times during this project I needed to challenge the language I used, removing words such as 'evidence', falling back into the quantitative construct.

As I continued to develop and grow as a qualitative researcher I found myself more firmly rooted within the constructivist paradigm. While always needing to remain reflexive throughout the research process I found that I less often moved towards my quantitative background. However, something I found to be particularly challenging was sharing the research findings with other health-care professionals, particularly surgeons. Being a surgical resident permitted a certain amount of ‘buy-in’ from the medical community. However, within the surgical community post-positivist thinking remains heavily engrained. In discussing the research findings I felt that I needed to have ‘one foot in both worlds’, representing the experiences of the study participants in a way that was reflective of them while ‘borrowing’ post-positivist language to gain acceptance from my quantitative audience. During this process I questioned ‘who am I’ as a researcher and as a surgical trainee, as I found that being a student of qualitative research who is a surgical resident and being a surgical resident who does qualitative research lonely in both ‘lives’. Would I ever be able to express the depth of this phenomenon to my surgical colleagues and would my research colleagues ever dismiss my post-positivist background? Extensive discussion with my supervisor (who had similar experiences) not only provided words of encouragement and direction, but also allowed me the opportunity to continue to mature as a qualitative researcher. Through discussions and reflexive journaling I have continued to grow throughout this project and will undoubtedly continue to do so in the future.

### 3.10 Ethical Considerations

As in any research study ethical considerations for this study included participant consent, maintenance of confidentiality, and appropriate storage of data (Morse & Richards, 2002). Given the nature of qualitative research, specific ethical considerations were also addressed: maintaining anonymity, the personal nature of the semi-structured interviews and the potential effects the research may have on participants (Orb, Eisenhauer, & Wynaden, 2000).

Permission to conduct this research study was obtained from the University of Toronto, as well as each of the hospitals which provided access to potential patient participants. Potential participants received a copy of the consent form along with their invitation to participate in the study (mail for patients and Ontario surgeons, email for U.S. surgeons). Interested participants were contacted to arrange an interview, during which time any questions about the research project were addressed.

Prior to initiating the interview, full consent was obtained. This process included reviewing the purpose and scope of the interview, the nature of the qualitative interview, the expected use of results including the maintenance of anonymity. In addition, the study participants were informed that they could withdraw from the research process at any point during the study. As the interviews consisted of open-ended semi-structured questions it was not possible to entirely predict the course or content of the interviews, therefore truly informed consent could not be obtained (Munhall, 1988). The changing and dynamic nature of the interview process is accounted for through *process informed consent* (Munhall, 1988). Rather than consent being static, it is an ongoing process, allowing both the researcher and the participant to readdress the consent/concerns with the study in the event of substantial (unanticipated) changes, unforeseen events or consequences occur (Munhall, 1988). As such, participants were informed that portions of the audio-recording could be stricken and the interview could be stopped at any time.

While qualitative research methods may make it difficult to predict the exact content of the interviews, this does not preclude the researcher from anticipating, and taking responsibility for, potential outcomes. It is known that research conducted on potentially sensitive topics may result in a powerful emotional response and potential distress (Orb et al., 2000). While it has been demonstrated that there is a potential cathartic benefit involved in qualitative interviews including the potential for empowerment, healing and providing a voice to the experience (Hutchinson, Wilson, & Wilson, 1994), there is also the need for the researcher to anticipate the potential for both positive and negative responses to the research process (Holloway & Wheeler, 1995; Orb et al., 2000). While some participants in this study became tearful during the interviews, they were not overwhelmingly distressed nor did they remain emotionally upset for more than a momentary duration. During such moments the interview was temporarily halted, the interviewer (AC) acknowledged the participants' vulnerability, and an offer to end the interview process was made (as in-keeping with process informed consent). In anticipation of potentially distressing responses the support of a counselor through one of the hospital sites was obtained, and the local resources available in the participants' treatment areas were identified. No participants requested that the interview be stopped nor obtained support through the resources offered.

Participants were assured that any potentially identifying information would be anonymized in their transcripts for analysis. While all participant transcripts were de-identified, the use of demonstrative quotes in the final analysis risks violating anonymity; this is particularly true for large blocks of quotes or notable quotes (Morse & Richards, 2002). In this study a thorough review of each transcript was conducted to ensure that participant's anonymity was not violated indirectly through demographics or other identifiable personal characteristics. In addition, large blocks of quotes which may have been potentially linked to participants were not included in their entirety to prevent identification. In addition, while personal information was obtained in order to identify potential participants, participants' interviews were in no way linked to personal information. Once participants agreed to be involved in the study, they were assigned a unique identifier number and all personal identifying information was removed from study data. Personal identifying information did not appear on any of the collected data.

Measures were taken to ensure the security of the collected data. All identifying data were stored on a secure, password-protected institute server via a password protected desktop computer. Hard copies of the consent forms were kept in a locked filing cabinet in a locked office. All digital recordings from the interviews were encrypted and stored on a password protected laptop computer accessible only by the principle investigator. The digital recordings were identified only by ID numbers and all personal information was removed during the transcription process. Interview transcripts, field notes and reflexive journaling were only identified by study number. Electronic versions of the interview transcripts were encrypted and kept on a password protected laptop. All raw data including transcripts, field notes, memos and journaling will be kept for seven years following this thesis publication.

## Chapter 4: “Taking Control of Cancer” – Understanding Women’s Choice for Mastectomy

This chapter presents the findings from the interviews which were conducted with women who underwent either UM or UM+CPM as treatment for their ESBC. It explores women’s diagnosis and decision-making experience. It has been published in the *Annals of Surgical Oncology*.

### **“Taking Control of Cancer” – Understanding Women’s Choice for Mastectomy** (Covelli, Baxter, Fitch, McCready, & Wright, 2014a)

#### 4.1 Introduction

In 1990 the National Institutes of Health consensus statement indicated that “breast conservation treatment (BCT) is an appropriate method of primary therapy for the majority of women with Early-Stage Breast cancer (stage 1/2) and is preferable because it provides survival rates equivalent to those of mastectomy while preserving the breast” (National Institute of Health, 1991). Before the release of this statement the majority of patients were treated with unilateral mastectomy (UM); however after 1990 the rates of mastectomy markedly decreased (de Koning et al., 1994; Gaudette et al., 2004; Harries et al., 1996; Lazovich et al., 1999).

Recently, numerous studies have documented the increasing use of both UM and contralateral prophylactic mastectomy (CPM) for unilateral ESBC, in women who are not at high-risk of developing a contralateral breast cancer (CBC) (Canadian Institute for Health Information, 2012; Dragun et al., 2012a; Dragun et al., 2012b; Gomez et al., 2010; Jones et al., 2009; Mahmood et al., 2013; Neuburger et al., 2013; Tuttle et al., 2007; Yao et al., 2010). Those patients who are considered to be at high risk of developing a CBC include: a personal or familial diagnosis of BRCA1/2, or other known genetic mutations including PTEN and P53, a personal history of ovarian cancer, a personal history of chest wall radiation and a strong family history of breast or ovarian cancer as defined by the National Comprehensive Cancer Network (NCCN) guidelines (National Comprehensive Cancer Network, 2014a, 2014b).

Nationwide studies using The Surveillance, Epidemiology, and End Results registries and the National Cancer Database, demonstrated a 10% rise in UM rate and 150% rise in CPM rates across all ages with ESBC (Mahmood et al., 2013; Tuttle et al., 2007; Yao et al., 2010). While surgeon, patient and system factors have been associated with the increased rates, they do not describe why this increase is occurring (Arrington et al., 2009; Benedict et al., 2001; Brennan et al., 2009; Houssami et al., 2013; Katipamula et al., 2009; King et al., 2011; Morrow et al., 2009; Nekhlyudov et al., 2005). Young, white, educated women of higher socio-economic status have been reported to choose mastectomy, however quantitative studies are unable to describe why women are making this choice (Hawley et al., 2014; Jones et al., 2009; Nekhlyudov et al., 2005; Tuttle et al., 2007; Yao et al., 2010). To further understand the current trends, and the role that women play in the increasing mastectomy rates, we conducted a qualitative study exploring patients' perspectives on decision-making for ESBC and women's choice for mastectomy.

## 4.2 Methods

### 4.2.1 Sampling and Recruitment

Women who had undergone either UM or UM+CPM within the previous 9-12 months (between Jan 2010-Jan 2011) were identified from 5 prospectively collected breast cancer databases from surgical centers (3 academic, 2 community centers) in the Toronto Area, Ontario, Canada. Chart review was then conducted to ensure that participants had ESBC, were not a high-risk of developing a CBC and suitable candidates for BCT (patients were excluded if they were pregnant at the time of treatment, had bilateral breast disease, or had absolute or relative contraindications for radiation therapy or breast conserving therapy as defined by NCCN treatment guidelines (National Comprehensive Cancer Network, 2014c). Participants were purposively sampled from these databases ensuring they varied in age, ethnicity and that comparable numbers of women who underwent UM and UM+CPM were recruited from each center. Purposive sampling is a standard qualitative technique where participants are selected based on having both undergone the experience and to reflect the diversity within a given population (Barbour, 2001; Coyne, 1997). This provided a wide range of motivations and perspectives on the surgical decision-making process. Our goal was to interview 2-3 participants from each surgical category (UM or UM+CPM) from each surgical center. Initial



contact with patients was made via a standardized letter inviting their participation in the study. The study was reviewed and approved by the institutional Ethics Review Boards.

#### 4.2.2 Data Collection

Grounded theory (GT) methodology directed the generation of the interview guide, data collection and data analysis (Charmaz, 2009; Lingard, Albert, & Levinson, 2008; McCann & Clarke, 2002). A conceptual framework was developed from a systematic literature review to aid the design of the interview questions. Four pilot interviews were conducted in-person, audio-recorded, transcribed verbatim, and then discussed among the research team (AMC, NNB, MIF, and FCW; AMC is a PhD candidate and a resident trainee in general surgery, NNB is a content expert in surgical oncology and a practicing general surgeon, MIF is an expert in qualitative research who focuses on oncology with emphasis on breast cancer, and FCW is a content expert in surgical oncology, a practicing breast surgeon, and an expert in qualitative research). The interview guide was then adjusted to ensure all areas of interest were addressed. One-on-one in-person interviews were audio-taped and performed by a single interviewer (AMC under the guidance of FCW). Saturation was reached after 29 interviews; this occurs when key concepts begin to recur and no new concepts emerge from the data (Guest, 2006). As saturation is often reached between 12-20 interviews in a heterogeneous population, a sample size of 29 is substantial in qualitative research (Kuzel, 1992).

#### 4.2.3 Data Analysis

Interviews were transcribed verbatim and GT was used to analyze the data. Constant comparative analysis is an iterative approach which involves multiple readings of the transcripts; simultaneous data collection and analysis generates a coding schema reflecting unique ideas (Charmaz, 2000, 2009; Lingard et al., 2008). Analysis of the schema allows similar concepts to be grouped together into larger themes (Charmaz, 2000, 2009; McCann & Clarke, 2002). Interviews were coded independently by two investigators, findings were discussed with the entire research team and consensus of interpretation was achieved.

## 4.3 Results

### 4.3.1 Patients and Interviews

40 individuals (8 from each center) were invited to participate in the study. Of these patients 10 declined participation: 4 patients could not participate in an interview in English, 2 refused due to disease progression, 1 had died, 2 had moved away, and 1 was ineligible as she had locally advanced breast cancer. An additional patient agreed but dropped out of the study prior to the interview for unknown reasons. Informed consent was obtained from the remaining 29 participants prior to participation. Interviews took place between September 2010 and January 2012. Median interview time was 71 minutes (range 50-91).

Median participant age was 55 (range 36-84). All patients had ESBC. Patient's had a diverse cultural and educational background. Most of the patients were married, 6 were not married (never married, divorced, widowed). 15 participants underwent UM (3 participants from each center) and 14 participants underwent UM+CPM (3 participants from 4 centers, and 2 participants from one center). 18 participants were treated at academic centers and 11 at community centers. Patient characteristics are presented in TABLE 3.

To illustrate the study findings, we have selected representative participant quotations to illustrate both typical responses and the range in views expressed. The examples are labeled by participant number and are drawn from women across the various recruitment sites, age, ethnicity and levels of education.

### 4.3.2 Themes

#### 4.3.2.1 *The Decision-Making Experience*

##### *1. Cancer Diagnosis*

Irrespective of whether the patients had been actively screening or inadvertently found their cancer all patients stated that the diagnosis of cancer was received with shock and fear, making comments such as

*"I was sure that my body was rampaged by cancer because I had breast cancer. I was panicked so panicked. Not only was I in panic mode about the decision about which surgery*

*to have, I was also in panic mode of, if I have the surgery was I still going to have cancer” (2)*

*“I was completely shocked because I expected everything to be fine. I was actually floored, shocked, but it was almost like in some ways, I had been expecting it for years” (15)*

*“You just hear the word ‘cancer’. And you just think, ‘Oh, my God. Like, I can’t believe this is happening to me’ because this thing doesn’t happen, you know” (18)*

## 2. Surgical Consultation and Discussion of Treatment Options

All patients recalled being informed that BCT and UM are equivalent treatment options for ESBC, and most recalled their surgeon stating that BCT and UM result in the same long-term survival.

*“She just described both procedures and asked me which I would prefer. Some women may have a lumpectomy and some have a mastectomy” (20)*

*“She told me that I could have the lumpectomy or mastectomy, but I preferred mastectomy. The chance of survival for a lumpectomy or mastectomy, there’s no – almost the same. There’s no difference” (3)*

*“Everything that I had read was that people who chose radical mastectomies, they don’t really need it. That’s what the research at the time said, that you can choose lumpectomy and radiation and it would be the same as basically a mastectomy” (17)*

The advantages and disadvantages of both BCT and UM were also reported as being routinely described by the surgeons.

*“I just remember she drew me the diagram she showed me (how she could remove the lump by using lumpectomy). I knew that this was a good recommendation because you can preserve the breast, right? This is very important because this is part of the body”. (7)*

*“I had the option for a lumpectomy– but if I had a lumpectomy, I would have to have radiation to reduce the risk of it coming back. If I have a mastectomy, I wouldn’t need radiation after. You can’t do reconstruction with just an implant on a radiated breast typically, if I had a lumpectomy, I wouldn’t be able to have reconstruction. Then even with a lumpectomy, she talked about chemo.” (13)*

While patients were aware that they would require radiation therapy (RT) after breast-conserving surgery, they were also informed that surgical choice would not impact the need for hormonal and chemotherapy.

*“I know if you do mastectomy, then there’s still a good chance that you have to do chemotherapy but very unlikely that you have to do radiation. But if you do lumpectomy, there’s a good chance that you have to do both (chemotherapy and radiation). I think for lumpectomy it’s almost a must to do radiation.” (7)*

*“Avoiding the radiation was important but here was also possibility of chemo. Well, I chose the mastectomy so I didn’t have to do radiation. When it came time to decide whether I have to do chemo, apparently there was this new test that helps you decide whether you can/have to take chemo or not..” (10)*

In this non high-risk population the discussion around CPM was always initiated by the patient.

*“Dr. B actually suggested that, you know, I shouldn’t have it removed (CPM). -I brought it up.” (6)*

*“Dr. C was very professional and very a matter-of-fact and very much ‘here is what we recommend. These are your choices (lumpectomy and unilateral mastectomy).’ I was out of the gate in that meeting. . . I said, ‘I’m already leaning towards having a double mastectomy’.” (9)*

*“I asked to arrange the mastectomy, and when I was talking to the surgeon I said I’d really like to go and do both.” (13)*

Surgeons did not recommend this procedure, and the patients were informed that having a CPM (in addition to UM) would not improve long-term survival. Women shared that they felt actively discouraged by their surgeons from such extensive surgery in this average risk population with no medical indication for CPM. This was particularly noted by those women who chose CPM.

*“She really cautioned me against it; didn’t want me to do that at all. She said ‘often women have this as a first reaction but it’s not going to change the outcome. It’s not going to extend your life” (13)*

*“I asked to arrange the mastectomy, and when I was talking to the surgeon I said I’d really like to go and do both. He said, ‘That’s a lot of surgery’. I felt like he was, you know, discouraging me” (14)*

### 3. Sources of Information

All patients described that the health care team served as an important source of information and described receiving information packages outlining treatment options.

*“I got information from (surgeon) and from the booklets. I searched the Internet but it didn’t tell me more than I already knew from the information that I got from my physician and my surgeon and the booklets.” (3)*

*“She (surgeon) drew a little diagram, where I stand on the sides of how bad it is; and pamphlets of course. Everything was useful” (13)*

In addition our patients described turning to multiple sources of information including books, the internet and occasionally support groups.

*“You know, I did as much research as I could. Everybody is online. I just looked at as many different sites as I could. I went to sites where they had different blogs where people would go through different things just to get a feel for it” (26)*

*“There were a number of staff people that worked there (local support group), and they actually referred me to talk to some of the patients. There is one particular patient and she was very helpful. She was telling me about all her (breast cancer) experiences” (6)*

*“One of the women I made very close friends with. She basically had gone through a mastectomy, before I did. She knew what it was all about and she was going in for her second one. She needed to have another mastectomy...Because I wasn't familiar with any of this, she was actually my mentor. I don't want to wake up every day and say, “Did it go over there?” (8)*

However, patients' most valued sources of information were stories from personal experiences of family or friends living with cancer. Patients described witnessing ‘*suffering though cancer*’, which left a lasting impression. The most influential of these experiences were loved ones who had been ‘lost to cancer’.

*“I had two friends die within a year previous from breast cancer. One had suffered with it for fifteen years and the other was ten. They both said to me, “I wish I had just taken them off”. (26)*

*“My aunt – she was the one who said – she only had the one breast removed. She was the one (when I told her that this is what I wanted to do) she said she felt that was a good idea because she had a lumpectomy originally and the cancer came back. That's when she decided to have the mastectomy. So, she was just like, ‘Just do it’. I think too because I had my aunt (and I had another aunt who had breast cancer as well), so I was able to get that firsthand rather than reading it from a book.”(25)*

*“Watching my mother die was really hard, incredibly hard. She was diagnosed in one year and exactly one year of the day of her diagnosis, she died. So it was fast, and I was the primary care giver, so it was very hard. I had been exposed to cancer, firsthand. My mother died in my arms” (2)*

It was clear that while all our participants encountered multiple sources of information, the most meaningful and influential in decision-making was the witnessed experience of family and friends with cancer.

#### 4. Understanding of Recurrence, Contralateral Breast Cancer (CBC) and Survival

Patients felt that they were at very high risk of developing an ipsilateral recurrence, a CBC, and the ‘spread’ of their cancer as distant metastasis; believing these events to be inevitable.

*“I’m just thinking if there’s breast tissue left there it’s coming back” (1)*

Patients believed there was an unavoidable step-wise progression between these events, with ipsilateral recurrence and/or CBC leading to metastasis and subsequently death. Despite surgeons discussing BCT and UM as equivalent treatment options for long-term survival our participants felt that there was an added survival benefit by having UM+/-CPM.

*“I wanted to take the course of action that was going to give me the best chance of survival. He was very clear to me to say that when the cancer is in the breast and it’s dealt with, it’s considered that it’s cured. I mean, he was using numbers for me, like 97-100% cure rate...By having the mastectomy, I would be removing not only the tumour, but hopefully a whole whack of rogue cells that might be still in the breast. I’m hoping that because I’d had the mastectomy, that I will be, you know, one of his patients that’s been cured” (15)*

*“(re. CPM) I’m looking for 45 years, not five. I’m not sure the survivability standard (the benchmark of 5 years), is a good benchmark. Certainly is in my world. I don’t want five years. I’d like to see my son who was three turn fifty. So, I really am looking for more like 45 or 50, you know?” (9)*

While patients were counseled that their index case of cancer was the most likely cancer to effect long-term survival, women expressed disproportionate concerns over the cancers that ‘**might**’ occur.

*“I’m not worried about my survival from this (treated side) - I’m worried about the other side” (3)*

*“Take these two breasts off. Now, that would have been not maybe the right decision but that didn’t scare me; I would be willing to take that risk so that I didn’t die from breast cancer at the age of 63.” (18)*

#### 4.3.2.2 *Reasons for Mastectomy*

##### 1. Choosing Unilateral Mastectomy

All participants shared their concerns around ‘*the cancer returning*’ as the reason for their choice of mastectomy. Certainty of the high risk of recurrence and death, resulted in participants choosing UM to eliminate this risk.

*“I made up my mind to do the mastectomy because I don’t want to live in the shadow of recurrence. I wanted to deal with it aggressively. I just wanted to kill it.” (7)*

*“I preferred a lumpectomy because of the changes in the shape of my body but I was afraid of recurrence. I decided to have a mastectomy because the most important factor for decision-making about mastectomy, was that of recurrence.” (3)*

Despite surgeons discussing BCT and UM as equivalent treatment options for long-term survival; participants voiced their beliefs that if all the breast tissue was removed then the ‘cancer couldn’t come back,’ and they would in-turn survive.

*“Just because there are survival numbers, doesn’t mean that is going to dictate my future. I figured that you know, by being aggressive with the treatment, I’m facilitating that.” (22)*

*“I didn’t want to risk just taking out one or two spots and then having to come back and deal with another surgery, and then six months it comes back. I didn’t want to be living with the situation where I had to constantly worry what’s left, and where and when it’s going to come back...The decision to have a mastectomy instead of a lumpectomy wasn’t hard. At that time, what was more important is the fact that I didn’t want to deal with – have this constant cloud over my head so I took the drastic (the more drastic) measure.” (10)*

Some women also chose UM to avoid RT. Those concerned about the effects of RT often had a previous experience with a loved one who had suffered from side effects of radiation treatment.

*“I saw side effects; my friend died from breast cancer years ago. My decision was if I ever get any disease that needs radiation, I will not do it. (23)”*

*“25-30 doses of radiation over my left side which is my heart, it doesn’t really appeal to me” (18)*

However, concerns around RT were secondary to the worry around recurrence and survival.

## 2. Choosing Contralateral Prophylactic Mastectomy

Similar to the UM patients those choosing UM+CPM voiced their fear around developing cancer in the contralateral breast.

*“The emotional impact of not knowing if you’ll have to do this again, the emotional stress of the worry that comes with, ‘is it going to come back’” (9)*

*“I think I would like to have a double mastectomy because one – is not enough for me... For me, I wouldn’t want to wake up every morning and think, ‘Oh, did it go there (other side) yet? Oh, did it travel there?’, because I know that’s what I would have done” (8)*

This fear prevailed despite discussions with the surgeons describing the low risk of developing a CBC. Participants felt by undergoing UM+CPM they would ensure they would ‘*never have to go through this again*’ and in-turn have a much longer survival.

*“I want them all removed. For me, it was all too much as one time. I don’t want to have to go back and do it again” (6)*

*“In my mind cutting it out was getting rid of it. I had convinced myself I was going to remove the breast and then I decided I was going to do the whole thing (and remove them both)” (25)*

*“Nobody is a 75% (survival). Nobody is a 90% (survival). Everybody is a zero or a one...I’d rather be a zero. For me, peace of mind, is the number one thing. The only way for me to have peace of mind is to not have it (contralateral breast).” (14)*

Some participants who had initially chose to undergo UM for their index cancer, ultimately underwent UM+CPM for symmetry. Women were informed that symmetry and balance would be better achieved if both breasts were reconstructed rather than trying to ‘*match*’ the reconstruction to the natural breast. However, concern around symmetry was secondary to fear of CBC.

*“I need to have it look symmetrical versus saving a breast for whatever have you. I knew that long-term I’d worry about cancer getting into my other breast” (19)*

*“My choice would be flat, because that also give me the peace of mind as well as the matching symmetry”. (14)*

#### **4.3.2.3 Post-operative Outcomes**

Only one patient explicitly questioned her decision for more extensive surgery yet, upon further exploration the majority of our patients did express either ongoing physical or psychological concerns. These concerns were predominately around body image and cosmesis.

*“I want to be comfortable in my skin, feel like a woman again, feel completely whole again” (9)*



*“I’m really very ashamed – I don’t want my husband to see me. I can’t show my husband my scar. I never show him my scars on my breasts” (11)*

*“I just wanted everything to be as normal as normal could be. With the clothes on, fine, you know? But nobody sees the other side at the end of the day when you take off your mask.” (12)*

Additionally a minority of our patients also had chronic pain, both nerve and from scar tissue:

*“Why does it bother me so much? Why can’t I live with the pain; the nerve is what’s burning” (23)*

*“Nobody explains to you what it is going to look like. Nobody explains to you the effect of scar tissue on the body. I’m in constant pain from the scar tissue.” (17)*

#### **4.3.2.4 Dominant Theme: ‘Taking Control of Cancer’**

‘Taking Control of Cancer’ is the dominant theme that emerged throughout the entire discussion. Women expressed that this surgical choice was theirs to make. While women participated in the surgical consultation, and turned to family and friends as sources of information, the final decision was made by our participants alone.

*“ Dr. C gave me choices. But I decided what was good for me....I had the double mastectomy” (8)*

*“I didn’t want somebody to just tell me, ‘You’re going to have it’ (regarding which surgery) without me thinking about it first. I want to be in control, you know? This is me. I have to be in control of what happens to me.”(21)*

Women believed they could manage both their fear of cancer and their cancer outcomes by choosing to have more extensive surgery; ensuring that they would ‘never have to go through this again’. More surgery was thought to definitively prevent ipsilateral recurrence and the development of a CBC; this in turn translated into the belief of improved long-term survival. In our women more surgery was seen as exerting greater control over their cancer.

*“You control it. You spend the rest of your life controlling it; hoping it doesn’t resurface. You have to take charge of it.” (16)*

*“But I finally was in control. So, I didn’t give a care if God said, ‘You’re going to have this.’ I’m going to make the decision, you know? It didn’t matter to me then, you see because I was in control now.” (18)*

## 4.4. Discussion

This is the first study to describe why women are choosing UM+/-CPM for treatment of ESBC in an in-depth fashion. We determined the decision to undergo mastectomy is a response to fear and anxiety; by choosing more extensive surgery women are attempting to control their cancer outcomes. Recent surveys conducted by Rosenberg et al. (2013) and Hawley et al. (2014) demonstrated that women choose CPM due to fear of recurrence, our study expands on these findings. Understanding how fear shapes women's decision to undergo UM+/-CPM will facilitate informed decision-making by enabling improved discussions around surgical care between health-care providers and patients.

A previous cancer experience with family and friends heightened our patients' fear, and played a notable role in our patients' decision-making. Literature has demonstrated that a previous cancer experience within the family produces feelings of vulnerability within family members, and shapes their cancer knowledge (Bernhardt, Geller, Holtzman, & Strauss, 1997). In hereditary breast cancer counselling, cancer risk and decision-making are interpreted through the experience of affected family members, rather than statistical probabilities (Kenen, Arden-Jones, & Eeles, 2004). Similarly, a diagnosis of BRCA generates a 'shared identity' between those newly diagnosed and previously affected loved ones (d'Agincourt-Canning, 2005). We found this 'shared identity' among our patients' resulted in women placing more emphasis on experiential knowledge than objective risk assessment.

The experiential knowledge shared by our patients was predominately negative, as patients recalled suffering and loss of affected family and friends. Similarly, patients who received information through networking with other patients recounted stories of recurrence and metastasis thereby regretting the choice for BCT. In keeping with previous literature, we found that despite the surgeons describing equivalent survival of the surgical options, subjective risk perception superseded objective information (Borgida & Nisbett, 1977; Redelmeier, Rozin, & Kahneman, 1993; Zikmund-Fisher, Fagerlin, & Ubel, 2010). Rosenberg demonstrated that despite being aware that CPM did not offer a survival benefit, women who underwent CPM over-estimated their risk of recurrence and chose CPM to 'avoid recurrence and extend their life' (Rosenberg et al., 2013). Similarly, our patients felt that they were at very high risk of local recurrence, the development of CBC, and their likelihood of disease-related death. Our patients' response to this misperception was to choose

UM+/-CPM, as they believed that survival would be different for them. By, choosing to have more extensive surgery our patients insisted that they had definitively increased their likelihood of living longer.

The perceived ability to control illness, and regulate emotional response in a threatening situation has been previously described in cognitive literature (Broadbent, Petrie, Main, & Weinman, 2006; Folkman, Lazarus, Gruen, & DeLongis, 1986; Petrie & Weinman, 2012). ‘Mastery’ has been defined as the extent to which an individual perceives their outcomes as being under their control (Pearlin & Schooler, 1978). Similarly, ‘exaggerated control beliefs’ are those where an individual attempts to control a situation where the outcome is unchangeable (Henselmans et al., 2010). It has been demonstrated that patients using mastery and exaggerated control as coping strategies are at higher risk of psychosocial morbidity, should disease recur (Tomich & Helgeson, 2006). All of our patients chose mastectomy as they wanted to **ensure** this would ‘*never happen to them again*’ demonstrating exaggerated control beliefs; in the setting of disease progression (an outcome not controllable through mastectomy) our patients may be at risk for a heightened deleterious psychological response.

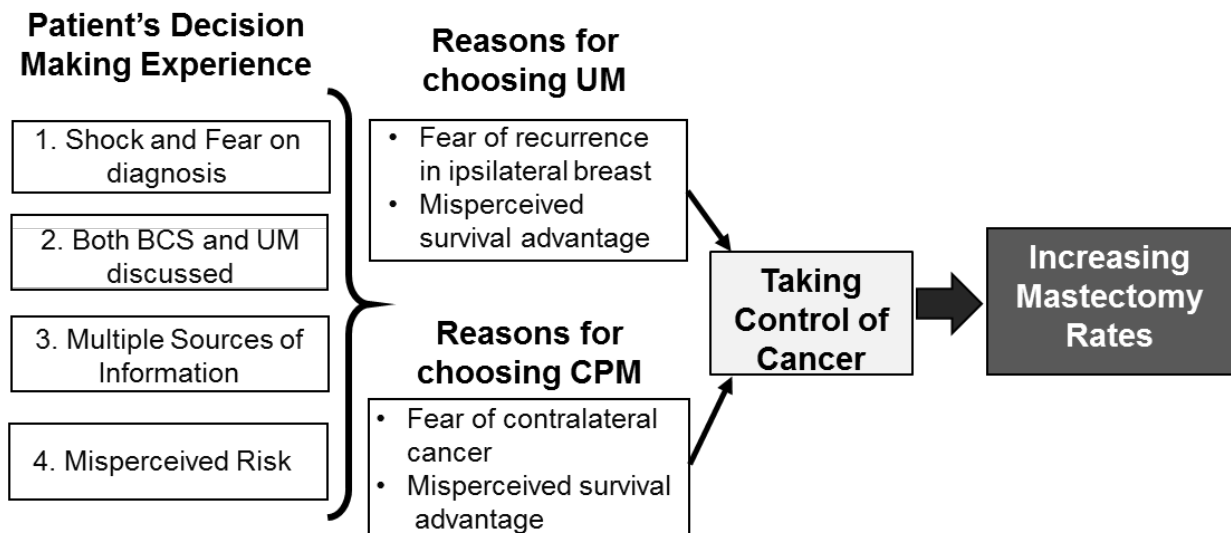
In women who are **not at high-risk** for CBC there are no guidelines that recommend CPM; a recent Cochrane update recommends against the use of CPM in non-high-risk women as there is no demonstrated survival benefit (Lostumbo et al., 2010). While CPM reduces the risk of CBC, this risk is already low in ESBC, with an estimated rate of 0.5% per year (lower in women undergoing adjuvant therapy) (Forbes et al., 2008; Gao, Fisher, & Emami, 2003; Nichols et al., 2011). Rosen et al. (1993) demonstrated that the vast majority of breast cancer deaths in women with ESBC are due to systemic spread of the index cancer, rather than the development of a CBC and subsequent death. However, undergoing CPM doubles the risk of potential complications associated with UM (Miller et al., 2013; Osman et al., 2013); major complications including infection, necrosis, bleeding, and reoperation occur in up to 16% patients after mastectomy of the non-cancerous breast (Goldflam et al., 2004; Miller et al., 2013). Long-term complications such as sensory skin disturbances and chronic pain have been reported by up to 50% of mastectomy patients and these may impact long-term quality of life (Brummett, 2011; Gartner et al., 2009; Tasmuth et al., 1995). Literature has demonstrated that while 85% of patients report overall satisfaction with CPM, qualitative assessment

demonstrates up to 84% of those who report overall satisfaction experience some dissatisfaction in the areas of body image, sexuality and chronic pain on the non-cancerous side (Altschuler, 2008; Frost et al., 2011). Many of our patients initially appeared content with their decision for more extensive surgery; on further exploration most participants shared concerns around body image, skin sensation and occasionally chronic pain.

With no evidence of medical benefit, and the potential for complications, comes an inherent tension between the patient's request for CPM and the surgeon's obligation to practice evidence-based medicine. This tension was reflected in our study as patients had to negotiate their request for CPM. As the benefits of undergoing CPM in the non-high-risk patient are minimal, we suggest additional strategies, such as decision-aids, to increase patient knowledge about the risks of recurrence, CBC and the net benefit of CPM. While current decision-aids do not include information about CPM, decision-aids have been demonstrated to improve patient knowledge around BCT and UM (Whelan et al., 2004). Decision-aids that incorporate both positive and negative patient narratives may alter patients' understanding of both the risks and benefits of treatment options (Bekker et al., 2013; Shaffer, Tomek, & Hulsey, 2014; Ubel, Jepson, & Baron, 2001); such tools could therefore be useful for women choosing CPM. Given the potential for long-term complications, the choice to undergo more extensive surgery needs to be accurately informed about risks associated with ESBC, the net benefits of UM+/-CPM, and not based solely on the belief that more surgery equates to better survival. As demonstrated in D'Agincourt-Canning's (2005) study, understanding how experiential knowledge shapes decision-making, and discussing patient's previous lived experience, can permit health-care providers to address the information that is most influential during the consultation process. Ensuring surgeons have an understanding about the role of fear and experiential knowledge in shaping a patient's choice for mastectomy, coupled with educational tools, may help inform the patient's decision-making process.

**Table 3: Patient Participant Characteristics**

<b>Unilateral Mastectomy</b>	<b>15 (n)</b>	<b>Contralateral Prophylactic Mastectomy</b>	<b>14 (n)</b>
<b>Location of Surgery</b>		<b>Location of Surgery</b>	
Academic Cancer Centre	6	Academic Cancer Centre	7
Academic Non-Cancer Centre	3	Academic Non-Cancer Centre	3
Community Centre	6	Community Centre	4
<b>Disease Stage</b>		<b>Disease Stage</b>	
Stage 1	9	Stage 1	6
Stage 2	6	Stage 2	8
<b>Age</b>		<b>Age</b>	
Range	42-84	Range	37-69
Median	56	Median	46
<b>Reconstruction</b>		<b>Reconstruction</b>	
Yes	3	Yes	8
No	12	No	6

**Figure 8: Conceptual figure describing those factors influencing the choice for mastectomy**

## Chapter 5 - Increasing Mastectomy Rates

### The effect of environmental factors on the choice for mastectomy: A comparative analysis between Canada and the United States

This chapter represents the findings from the interviews conducted with both Ontario and U.S. surgeons. It explores the surgical consultation for ESBC. It also demonstrates the how the health-care environment might influence the choice for mastectomy both through patients' decision-making as well as by shaping the surgical discussion. This chapter has been published in the *Annals of Surgical Oncology*.

#### **Increasing Mastectomy Rates -The effect of environmental factors on the choice for mastectomy: A comparative analysis between Canada and the United States** (Covelli, Baxter, Fitch, & Wright, 2014b)

### 5.1 Introduction

In 1990 the National Institutes of Health consensus statement indicated that “breast conservation treatment (BCT) is an appropriate method of primary therapy for the majority of women with Early Stage Breast cancer (stage 1/2) and is preferable because it provides survival rates equivalent to those of mastectomy while preserving the breast” (National Institute of Health, 1991). Before the release of this statement the majority of patients were treated with unilateral mastectomy (UM); after 1990 rates of UM markedly decreased across the United States (U.S.), and Canada (Gaudette et al., 2004; Lazovich et al., 1999). Numerous studies have demonstrated the increasing use of both UM and contralateral prophylactic mastectomy (CPM) for the surgical treatment of ipsilateral ESBC in average risk women (Arrington et al., 2009; Dragun et al., 2012a; Dragun et al., 2012b; Gomez et al., 2010; Jones et al., 2009; Katipamula et al., 2009; Mahmood et al., 2013; McGuire et al., 2009; Tuttle et al., 2007; Yao et al., 2010). U.S. nationwide studies demonstrated a 10% rise in UM rate and 150% rise CPM rates since 2000; with CPM rates between 7-11% of all women with unilateral cancer (Mahmood et al., 2013; Tuttle et al., 2007; Yao et al., 2010). Similarly, a nationwide study from Canada demonstrated a rise in CPM for unilateral cancer, increasing from 5% to 7% between 2007 and 2009 (Canadian Institute for Health Information, 2012).

Multiple factors have been attributed to the increasing rates of UM+/-CPM including: use of MRI, access to reconstruction, surgeon's preference, and patient choice (Benedict et al., 2001; Brennan et al., 2009; Katipamula et al., 2009; King et al., 2011; Morrow et al., 2009; Nekhlyudov et al., 2005). Katipamula et al. (2009) noted MRI rates increased from 10% to 23% between 2003 and 2006, during which mastectomy rates rose from 31 to 43%. Other studies have demonstrated that pre-operative MRI increases the likelihood of mastectomy 2-3 times (Houssami et al., 2013; King et al., 2011; Miller et al., 2012). Similarly, multiple institutional studies have reported positive correlations between access to reconstruction and rates of mastectomy (Damle et al., 2011; King et al., 2011; Stucky et al., 2010).

Importantly, the widely documented increase in mastectomy rates cannot be entirely explained by MRI or reconstruction (Guilfoyle et al., 2014; Katipamula et al., 2009; Stucky et al., 2010); it has been suggested that both the surgeon's preference and patient choice may be playing a role. Studies have described women playing a more active role in their decision-making, choosing to undergo mastectomy (Collins et al., 2009; Hawley et al., 2007; Katz et al., 2005a). Other studies have documented that the surgeon influences whether a patient chooses UM or BCT (Arrington et al., 2009; Katz et al., 2001; Morrow et al., 2009; Reitsamer et al., 2008), although this literature is mixed as the influence of the surgeon has been associated with both BCT and UM (Morrow et al., 2009; Reitsamer et al., 2008).

In light of the increasing mastectomy rates we wished to qualitatively explore what role the surgeon and their practice environment plays in the increasing rates of UM+/-CPM.

## 5.2 Methods

### 5.2.1 Sampling and Recruitment

Eligible surgeons included those who completed a general surgery residency, practiced independently for at least five years, were still in active practice and did not subspecialize in a field unrelated to breast cancer. Potential Ontario participants were identified through the Canadian Medical Directory; surgeons were then purposively sampled ensuring they varied in location of practice (academic and community), length of practice, extent of training, and gender. Purposive sampling is a standard qualitative technique where participants are selected based on having both

undergone the experience and to reflect the diversity within a given population (Barbour, 2001; Coyne, 1997). In the United States key informants were contacted and snowball sampling identified potential participants. Surgeons were then purposively sampled ensuring they varied in the aforementioned characteristics. Initial contact with surgeons was made via a standardized letter inviting their participation in the study.

The study was reviewed and approved by the institutional Ethics Review Boards.

### 5.2.2 Data Collection

Grounded theory (GT) methodology directed the generation of the interview guide, data collection and data analysis (Charmaz, 2009; Lingard et al., 2008; McCann & Clarke, 2002). A literature review aided the design of the interview questions. Four pilot telephone interviews were conducted, audio-recorded, transcribed verbatim, and then discussed among the research team. The interview guide was then adjusted to ensure all areas of interest were addressed. One-on-one telephone interviews were audio-taped and performed by a single interviewer. Saturation was reached after 45 interviews. Saturation occurs when identified concepts begin to recur and no new concepts emerge from the data (Guest, 2006) and is often reached between 12-20 interviews in a heterogeneous population (Kuzel, 1992).

### 5.2.3 Data Analysis

Interviews were transcribed verbatim and GT was used to analyze the data. This is an iterative approach which involves multiple readings of the transcripts; simultaneous data collection and analysis generates a coding schema reflecting unique ideas (Charmaz, 2000, 2009). Constant comparative analysis of the schema allows similar concepts to be grouped together into larger themes (Charmaz, 2000, 2009; McCann & Clarke, 2002). Interviews were coded independently by two investigators, findings were discussed with the entire research team and consensus of interpretation was achieved.



## 5.3 Results

### 5.3.1 Participants and Interviews

*Surgeons:* 70 surgeons (40 Ontario and 30 U.S.) were invited to participate in the study. Of these 13 declined participation: 3 no longer practiced, 4 did not treat breast cancer, and 6 did not participate in research interviews. An additional 11 surgeons did not reply to the initial or follow-up invitation. The remaining 45 (23 Ontario and 22 U.S.) surgeons consented to participation.

Interviews took place between March 2012 and April 2013. Median interview time was 43 minutes (range 26-93).

Surgeon characteristics are presented in TABLE 4.

### 5.3.2 Common Findings (U.S. and Canada)

All surgeons at academic and high-volume breast centers noted an increase in rates of UM and notably UM+CPM. All surgeons described both BCT and UM as equivalent options for the treatment of ESBC, resulting in the same long-term survival. The advantages and disadvantages of both BCT and UM were routinely described to women. To illustrate the study findings, we have selected representative participant quotations (number in parentheses indicates participant number ON=Ontario surgeon US=United States surgeon)

*“I’m doing more mastectomies than I was. I’m seeing more and more people who I would think would not want a mastectomy choose a mastectomy (21-ON)*

*“There seems to be a slightly higher percentage of people who are interested in mastectomy right off the bat. There is a slightly higher (I’ve seen more often) people are looking at contralateral prophylactic mastectomy.” (13-ON)*

*“In the last little while there were quite a number of women requesting bilateral mastectomies from several of our surgeons..” (18-ON)*

*“Maybe last ten years or five years we all have seen an increase in mastectomy rates” (4-US)*

*“I know our mastectomy rates here is right around 50%. But, we definitely have a lot of a patients who want to do a contralateral prophylactic mastectomy.” (5-US)*

*“They (re. rates) have certainly gone up tremendously over the last few years. It’s gone up tremendously I do lots and lots of bilateral mastectomies for unilateral disease.” (14-US)*

*“The floodgates opened. If you asked me I would say four years ago. I will say though, if you look at our records just like everybody else, we’ve done more bilateral mastectomies in the last three years than we did in the previous ten.” (18-US)*

### 5.3.3 Themes

#### 5.3.3.1 Ontario Surgeon’s Practice

Ontario surgeons frequently recommended BCT, but ultimately, it was the patient’s choice. The role of Canadian Guidelines was the basis for recommending BCT.

*“There are two surgical options, one is lumpectomy one is mastectomy...Both of these options are the same in your chance of getting cured. Then we have to look at the pros and cons” (3-ON)*

*“I always describe to them lumpectomy versus mastectomy. I describe both approaches. I describe the side effects, and the data we have on each procedure?” (1-ON)*

*“In the past whereas I just used to ask them to make a choice based on the information that I’ve given them. Yeah, now I actually provide a recommendation” (8-ON)*

*“I would generally encourage people to have a lumpectomy ...I tend to prefer lumpectomy if possible.” (12-ON)*

*“When I tell them to do the breast conserving surgery because you can always go forward with a mastectomy if they are not satisfied with the breast conserving surgery or it’s not feasible. But once we do a mastectomy we can’t go back. I encourage them to do the least amount of surgery possible to get done what it needs to be done.” (18-ON)*

*“I talk about if the tumor is amenable to a lumpectomy, I tell her that the recommended treatment by the Canadian guidelines is that I’m supposed to offer a lumpectomy and radiation. But I always tell her that the other option is a mastectomy for the known breast cancer ....I reiterate that the recommended procedure is to have the lumpectomy. ... If the patient is a candidate for lumpectomy, I tell them to do a lumpectomy”(2-ON)*

*“For the lumpectomy patients, well, the standard of care if you can have a lumpectomy is to have a lumpectomy. So if you can’t decide why don’t you go ahead with that because that’s what recommended in the Canadian guidelines.” (2-ON)*

*“We are just recommending what’s statistically or evidence to us, best practice without being dogmatic about it.” In the sense that we don’t tell people you have to have a partial and not a mastectomy..” (9-ON)*

In this average-risk patient population CPM was not recommended as a treatment option. The discussion of UM+CPM was initiated by the patient, and was often discouraged by the surgeons; who described the lack of survival benefit, potential delay in adjuvant treatment, and suggested they initially treat only the index cancer.

*“It (CPM) almost always it originates from the patient. In my practice, it almost always comes from the patient. We choose our local treatment. Then, most of the time it’s like they make an appointment or they call later and say, “Can I have both off?” (22-ON)*

*“They come in initially, they tell me, “Okay I want a mastectomy and bilateral mastectomy.” (1-ON)*

*“If they ask for the prophylactic on the other side, I usually give an argument against it. I say, ‘There is no evidence of cancer on the other side. Yes, you are a risk because you’ve now had cancer but realistically, you don’t necessarily need and we don’t conventionally do a prophylactic just on this basis alone’.” (9-ON)*

*“I make sure they understand what the risk is to the other breast, that they are at higher risk from the index side. ...I say ‘Minimize your surgery and the risk of any complications. Deal with the affected side.’” (17-ON)*

*“I tell them about the fact that I don’t like anything complication-wise to be affected on the other side that would potentially delay treatment of the primary cancer. So, I reiterate that the reason I don’t like to do the other side at the same time is that if there is something bad to happen, I may delay the treatment, right?” (11-ON)*

Reconstruction options were not routinely discussed among the initial treatment options but rather, were introduced when a patient was considering mastectomy.

*“I also bring up the issue of breast reconstruction; should they choose mastectomy” (10-ON)*

*“Once it is clear that, that’s the direction they want to go then we will discuss what they can expect afterwards and that there is a possibility of reconstruction” (7-ON)*

*“Even if they don’t need a mastectomy but they decide they want that route, then I will talk about the different types of mastectomy and I’ll talk about reconstruction.” (11-ON)*

The timing around this discussion was in-part reflective of access to immediate breast reconstruction (IBR). While all Ontario surgeons had access to delayed reconstruction, access to IBR was variable and predominately limited to academic and high-volume breast centers.

*“Our surgeons at (hospital) are willing to incorporate inconveniences and inefficiencies in order to try and improve access for women who want reconstruction. It happens to be an interest of ours. So, you know, we’re willing to put up with all of these barriers. I think our access is better.” (19-ON)*

*“When I was at a different site, access to immediate reconstruction was higher. I’ve relocated to a different site where access is much lower” (8-ON)*

*“Immediate reconstruction (practically speaking) is not really available. Delayed reconstruction, yes.” (7-ON)*

*“Unfortunately, patients cannot be served in (city) because we don’t have a plastic surgery who does the immediate reconstruction.” (14-ON)*

All surgeons had access to MRI, however few used MRI routinely for breast cancer patients. Surgeons described a selective approach to MRI due to its high sensitivity and low specificity. Surgeons also described the need to counsel patients about the potential advantages and disadvantages of MRI.

*“I warn patients that MRI is very sensitive so that they don’t be surprised if they get a call back for second look ultrasound. I think you have to prepare them for that mentally because once they have been diagnosed with breast cancer, they get very concerned about any abnormalities that might pop up and immediately think that because there is more extensive disease. So I do warn them that there is a high chance that they may get called back, but that does not necessarily mean that there is more disease.” (6-ON)*

*“But I try to talk them out of it. If it’s not needed it’s not needed. I do tell them that the MRI will tend to overcall things.” (3-ON)*

*“We have a close dialogue with the radiologists. I personally do not do an MRI on every patient that the radiologist wants to do an MRI on” (19-ON)*

*“Initially, we fell on the band-wagon. We are pretty much thinking that everybody should have it. That was promoted by our radiologists who wanted to get some experience at breast MRIs. But what I found was that over time it caused delays, further investigation of other benign lesions. Occasionally it did contribute to a change in management but caused just as much on the downside as well. Now, certainly I’m doing it selectively.” (22-ON)*

### 5.3.3.2 U.S. Surgeon's Practice

All U.S. surgeons described both BCT and UM and many surgeons initiated discussion around reconstruction early in the initial consultation.

*“I explain to them that there are two major types of surgery. One, being removing part of the breast and one being removing the entire breast as we can see it. We go through the pros and cons starting from the premise that whichever one they choose is unlikely to change their long-term survival outcome.” (1-US)*

*“I tell them that if they had an identical twin your twin could have the lumpectomy. You could have the mastectomy. We talk about the idea of the equivalent outcomes. You would have lost your breast and your twin wouldn't have for – and your outcomes are going to be the same assuming, you know, you're matched in every way.” (11-US)*

This approach is reflective of both the widespread availability of IBR, with nearly every surgeon describing ready access, as well as legislation which mandate that all surgical options, including reconstruction, be described at the initial consultation.

*“I tell them for treatment of the breast we still treat the entire ipsilateral breast with mastectomy with or without reconstruction or lumpectomy with radiation therapy and tell them the long-term survival rates are the same.” (6-US)*

*“I'll discuss with them the differences between breast conservation therapy with lumpectomy and radiation versus mastectomy with or without breast reconstruction. So, we go through each one of those options with them” (12-US)*

*“If they are deciding that a mastectomy is the way they want to go then I say, “Well, we will have you see the plastic surgeon...I get them (plastic surgeons) involved pretty much right away. My access is good at our hospital. We have two surgeons who are quite keen to take care of the breast cancer patients and do reconstruction.” (10-US)*

*“Very accessible. They can have autologous. They can have whatever they want. We can get them in within 2 to 4 days into a plastic surgeon. Our plastic surgeons are willing to do immediate reconstruction. I'd say the vast majority of our reconstructions are immediate and not delayed.” (3-US)*

Surgeons described that state and federal laws mandated the discussion of reconstruction and balancing procedures and that insurance companies cover these costs for women who undergo mastectomy.

*“Every patient here gets a book about breast cancer that's mandated by law which discusses lumpectomy and mastectomy options. There is a manual that is state-approved*

*that must be handed out irrespective if they've made a decision or not.” (1-US)*

*“I am obligated by law to offer every single woman a breast reconstruction...So we offer mastectomy to everyone.” (11-US)*

*“Women's health and cancer rights action that was passed in 1998 that said that insurance companies needed to cover reconstruction as part of the treatment of breast cancer.” (7-US)*

*“In the United States there's actually a federal law that the insurance has to cover the reconstruction if you have a mastectomy, and it has to cover whatever is done to the other breast to make it match” (16-US)*

U.S surgeons frequently did not put forth a treatment recommendation although if directly asked by the patient some surgeons recommended BCT, while others refrained, stating the decision was entirely the patient's choice.

*“When I actually give my talk, it is geared towards breast conservation therapy. It's not a recommendation. I give them both. They hear both. What I get at the end is, sometimes they go, 'Well, why did you mention mastectomy?' I go, 'Well, I have to give you your options so you could choose.’ (17-US)*

*“I try to avoid putting forth any recommendation until they have expressed what they are making their decision on. At that point – if they ask me for recommendation, I say, “Tell me again what is it important to you? Of the types of women I described, what sounds more like you?” Then we go through from there. I'll help guide them to a decision,” (1-US)*

*“There's a lot of patients that I don't make a recommendation in. I might lean towards a lumpectomy... or mastectomy, but it's really their decision” (5-US)*

*“I always go through the same information with everybody. If they say, “Well, this is what I want to do regardless.” I say, “Okay. That's fine.” (16-US)*

In an average risk population, U.S. surgeons did not discuss CPM as a treatment option, rather patients initiated this conversation. Many U.S. surgeons did not advise strongly against this request; risks and benefits were always discussed but it was often left to the woman's choice.

*“It seems many, many women come to see us with the idea in mind that they are going to have bilateral mastectomies.” (8-US)*

*“Now it seems more that when they ask about (CPM) they are like, 'I'm definitely having this' as opposed to just sort of bringing it up for discussion. But in general we tell*

*patients it's not something that we recommend unless there are medical issues that really, you know, would push us in that direction. But in general we will not to encourage patients to undergo bilateral mastectomy" (9-US)*

*"You know, I'm very careful to make sure the patients understand the pros and cons of all these mastectomies (UM+CPM). But in the end, if I think they understand it, it's fine with me. "(14-US)*

*"I spend a lot of time personally discussing the pros and cons of each approach. I always tell them...there is no data that shows that there is a survival advantage to bilateral mastectomy. There is a risk of reduction of contralateral breast cancer but you have to weigh that against the potential of developing that. I said, there are other pros – you know, there are symmetry issues. You know, so I just say, "If that's your feeling, I think that's fine. We do this all the time" (17-US)*

*"(re.CPM) I always try to discuss the data available.... But I always tell them it's ultimately their decision and that's fine but I need to feel like they have all the information before making that final decision" (19-US)*

Most U.S. surgeons described an 'all or nothing' phenomenon with women deciding between BCT and UM+CPM with IBR.

*"It's not a choice between a lumpectomy and mastectomy. It's the choice between lumpectomy and bilateral mastectomies. The unilateral has sort of gone out the window. I would say that my unilateral rate versus bilateral is probably 20-80. The vast majority want bilateral." (US-3)*

*"I don't think it's very common where they have the option of a unilateral breast conservation and they choose a unilateral mastectomy. They will most likely jump to a bilateral mastectomy. If they are going to jump to a mastectomy, they will generally jump to a bilateral mastectomy." (14-US)*

*" It's like an all or nothing thing now. There's less unilateral mastectomies because here's more bilateral mastectomy choice. , you know, women either want breast conservation or, 'Gee. If I'm going to do it, let's just get rid of all of it.' " (US-18)*

All surgeons had ready access to MRI. While most U.S. surgeons preferred selective use of MRI in ESBC patients, many commented that MRI was often completed at an outside imaging facility at the time of diagnosis, prior to the surgical consultation, thereby removing the surgeon's potential to limit and/or counsel the patient prior to MRI use.

*"A number of our patients will already have had a breast MRI if they were diagnosed*

*externally. If they were diagnosed with another provider, that provider probably would have already done a breast MRI on a patient.” (12-US)*

*“In many cases it’s done in the diagnostic clinic before I see the patient (which in situations I don’t favor). I don’t like how the radiologist ordered the MRIs. I’d rather do it myself if I need.” (6-US)*

*“A patient went in for screening mammogram identifies a mass in the upper outer quadrant in the left breast. Then she has an MRI of the breasts ...the report of the left breast shows multiple nodules and multiple enhancing nodules of the right breast as well. So the trouble with MRI is that it wasn’t necessary in her. If it’s not actually utilized carefully and thoughtfully, you run into problems. Now this lady says to me, “I want both of my breasts removed.” (11-US)*

### **5.3.3.3 Dominant Theme: The effect of external factors on the choice for mastectomy**

All surgeons reported that those women who underwent more extensive surgery, particularly UM+CPM, did so based on the patient’s choice and not the surgeon’s recommendation however, there are a number of external factors that appeared to make this choice more likely.

*“What I find more often is that the patients who elect to go with the mastectomy will say, ‘Okay, can I have double mastectomy?’ Like if the patient who still want mastectomy will say, “Can I have a prophylactic mastectomy on the other side at the same time?” (1-ON)*

*“I’ve had a bunch of them who want a bilateral mastectomy. They want the cancer of the breast off. Then they want their other healthy one off too.” (22-ON)*

*“They’ve already got it set in their mind that they want to do (re CPM). You know, they’re young – they’ve just decided to go ahead” (17-ON)*

*“I’ll have patients, you know, come in and say, ‘I’ve got this stage I breast cancer’ and they say they want double mastectomies. I will go through everything. I’ll tell them, ‘You know, your survival is the same. Your recurrence is the same. If you have a double mastectomy, you’re going to have more complications. You’re going to have a longer recovery.’ They will listen politely and say, ‘Thank you very much. When are you going to schedule my double mastectomy for me?’ (6-US)*

*“It’s not the surgeons pushing it (re. CPM). It’s the patients who are pushing it”. (14-US)*

*“Once someone has made up their mind, they made up their mind. Okay? They are going to do that regardless of what you tell them. There are some women that are very adamant, ‘Listen. I want bilateral mastectomy.’ (4-US)*



Use of MRI, access to immediate reconstruction and effect of legislation and guidelines, were all external factors which impacted the patient's decision to undergo mastectomy.

Many surgeons (Ontario and U.S.) expressed the potential influence that MRI findings had on the decision for more extensive surgery, even in the setting where new findings were not malignant. Despite surgeons counselling patients on the clinical significance of additional (often benign) findings, many patients opted for UM+/-CPM because of the induced fear of another 'lesion' in the breast. In addition, when the MRI was conducted prior to the surgical consultation, surgeons frequently described trying to 'undo' the impact of those MRI findings.

*"Is it what is causing women to go to bilateral, MRIs? They've just had it, if you say there's something wrong on the other side that needs a biopsy, they say 'Forget it. I want both of my breasts removed.'" (3-US)*

*"Certainly there were those cases of patients who got a breast MRI and a whole bunch of stuff showed up. You do the mastectomy and most of that stuff is nothing anyway, but it's enough to alarm some patients and they got mastectomies" (19-US)*

*"(re MRI) If we do find something similar in the breast, that often leads to an automatic mastectomy because it's multifocal disease even though we don't know – actually, with the newest research (clinically) it probably is insignificant" (14-US)*

*"MRI has a lot of false positives. Most of the time, they end up being nothing when you do the biopsies on those. The patients – there is this fear that, based on the fact that it's shown up on the MRI that even though the biopsy is negative, they are/still want to have a mastectomy" (11-ON)*

*"I would say probably about five years ago we were doing more MRIs and we were picking up a lot of stuff that required more biopsies, and more work-up...multi-centric disease and atypical stuff like that we might have otherwise treated surgically.. So yes, I do think that there were more MRIs and more mastectomies being done." (20-ON)*

*"You know that the MRI is not going to reassure them. The MRI report never says that there is nothing anywhere in the breast. An MRI sees everything and our radiologist of course describes everything they see. When a lay person reads that description, it can be very frightening." (21-ON)*

Both Ontario and U.S. surgeons described how access to IBR seemed to influence a patient's choice for more extensive surgery, with some surgeons describing an inverse relationship between patients

undergoing BCT and the availability of IBR. This was particularly well described by those surgeons whose access to IBR had varied over the course of their recent practice. These surgeons noted more women undergoing UM+CPM in centers where access to IBR was readily available.

*“Because of the significant change five or six years ago with huge availability (of reconstruction) or competent and easily access surgery, and see how that drove the contralateral mastectomy.” (3-ON)*

*“It’s really all just driven by our ability to offer this high quality reconstruction and the referrals they we are getting from far and beyond. I think that’s a big proportion. That side (re. CPM), for sure is doubling and tripling.” (17-ON)*

*“The availability of plastic surgery made a huge difference. We had some of the best plastic surgeons in the world, they technically were so good. They were not afraid of free flaps at all. We could do it quickly. You had to watch it because if a woman asked, they would do both sides. In other words, I did have one or two patients who only needed a lumpectomy and they got both sides done because of the availability and the enthusiasm of our plastic surgeons”(ON-2)*

*“For about three years had a plastic surgeon full time in town. When she was there, my mastectomy with reconstruction rate went up. Patients given the option of staying in town having mastectomy and immediate reconstruction, liked it and so we did more. When the patients didn’t have the option, not many but a few, would opt for mastectomy and then delayed reconstruction later out of town. The fact that it wasn’t convenient to do immediate reconstruction, might have influenced their decision to stick with breast conservation therapy” (19-US)*

*“The rates of breast conserving surgery and rates of reconstruction are inversely related. So, if you have more reconstructive surgeons, waiting times are lower and you are able to get those patients into the OR quicker. People are more likely to do mastectomy with reconstruction...influence your rates of breast conserving surgery.” (7-US)*

Similarly, those surgeons in Ontario centers where access to IBR was limited, experienced fewer women choosing UM+CPM. In addition, the consultation process with the reconstructive surgeon and patient’s desire for symmetry were factors influencing a woman’s choice for CPM. Some women who had previously decided upon a UM for their ESBC ultimately underwent UM+CPM as better symmetry would be achieved with bilateral reconstruction as opposed to ‘matching’ the natural breast.

*“If you don’t remove your other breast, than I can’t make it match perfectly.’ I think that*

*comes up all the time because after they've seen the plastic surgeon then they call us back and say, "Oh, I've decided to do both sides (16-US)*

*"Some people will make up their mind based on the need for unilateral mastectomy and then discussion with the plastic surgeon for contralateral reconstruction." (21-US)*

*"They are aware of a lot of the benefits in terms of bilateral mastectomy for the reconstruction in terms of achieving symmetry and having a superior cosmetic outcome with a bilateral mastectomy compared to a unilateral mastectomy" (US-2)*

*"If they are getting some type of DIEP or free tissue flap, I will have another discussion with them saying they don't need to have a prophylactic mastectomy. But a lot of them will opt for it because of symmetry" (12-US)*

*"I see a lot of women referred through plastic surgery. They think 'okay well I actually want to do a CPM with bilateral reconstruction. They want to get good symmetry.' (6-ON)*

*"Their wording is usually, 'Well, if you are going to take one off. Why don't you take both off? Might as well do that just so I can be symmetrical' or 'what's the point of having one breast if the other one is gone?' (11-ON)*

U.S. surgeons described both federal and state laws as impacting both the surgical discussion as well as the patient's accessibility to reconstruction. Some state laws mandate that all surgical options, including the option for reconstruction, be discussed at the initial consultation. The resultant surgical discussion was often presented in a manner where the surgeon simply stated all the options without putting forth a recommendation, and the treatment choice was left entirely up to the patient. While surgeons were not encouraging women to undergo more extensive surgery the presentation of surgical treatment as a list of options may allow women to more readily choose UM+CPM particularly with IBR (TABLE 5).

## 5.4 Discussion

The phenomenon of increasing mastectomy rates for treatment of ESBC has been experienced nearly universally by the surgeons in our study and, more notably, the patients initiated the request to undergo UM+CPM. Factors that appeared to affect this request included incidental findings on MRI, ready access to reconstruction, and the surgeon's initial discussion of treatment options.

In our study, both Ontario and U.S. surgeons had good access to MRI. Frequently U.S. surgeons, and occasionally Ontario surgeons, described patients having undergone MRI prior to meeting the surgeon (often at an outside imaging facility). This finding reflects a recent survey which described that 74% of imaging practices routinely offered MRI to patients diagnosed with breast cancer; 61% were independent of a hospital (Bassett et al., 2008). It has been clearly demonstrated that MRI offers superior sensitivity to mammography but is inferior in specificity with a high false positive rates (Kreige et al., 2004). Use of MRI has been positively correlated with an increase in UM by 1.8-3.0 times and CPM by 2.0-2.8 times (Houssami et al., 2013; King et al., 2011; Miller et al., 2012; Sorbero, Dick, Burke Beckjord, & Ahrendt, 2009). A recent meta-analysis found that MRI did not improve short-term surgical outcomes, and was associated with an increase in mastectomy rates, suggesting the routine use of pre-operative MRI has an unfavorable risk-benefit ratio (Houssami et al., 2013; Hwang et al., 2009; Solin et al., 2008). While surgeons were aware of the disadvantages of MRI and discussed them with patients, an MRI completed prior to the surgical consultation removed the opportunity to counsel patients about potential short-comings, and in-turn influenced the patient's choice for mastectomy.

Access to reconstruction and reconstructive options also appeared to influence a patient's choice for mastectomy. In contrast to the wide availability of IBR in the U.S., access to IBR within Ontario was variable. In 2008 reconstruction rates within Ontario were 23.3% with only 11.7% performed as IBR, (Platt, 2013) whereas, U.S. rates were reported as high as 29% for IBR in population-based studies and 40% across a network of tertiary care centers (Christian et al., 2006; Kruper et al., 2011). The variation in access to IBR across Ontario influenced the surgical consultation. While all women who were considering mastectomy were referred for reconstruction, surgeons with limited access to IBR often preferentially discussed, and encouraged, patients to undergo delayed reconstruction. Interestingly, Ontario surgeons practicing in low access areas in our study described how motivated patients would travel to gain access to IBR but this was a minority of patients, a finding that was corroborated by Platt et al. (2013). The discussion with the plastic surgeon also influenced a patient's request for more extensive surgery. In our study, many U.S. and some Ontario surgeons described the phenomenon where patients who had initially chosen UM, returned requesting UM+CPM following a consultation for IBR. Patients had often been informed that better symmetry would be achieved through bilateral reconstruction and this appeared to influence the choice for

more extensive surgery. Numerous studies have demonstrated positive correlations between women undergoing UM+CPM and IBR (Chung et al., 2012; Damle et al., 2011; King et al., 2011). Houn et al. (1995) demonstrated that compared to general surgeons, plastic surgeons were more likely to recommend bilateral mastectomy in a setting where the plastic surgeon deemed the patient was at higher risk of recurrence. The role that symmetry plays in the choice for mastectomy has not been well described; a future direction of this study would be to better delineate the effect that the reconstruction consultation may have on the choice for UM+CPM.

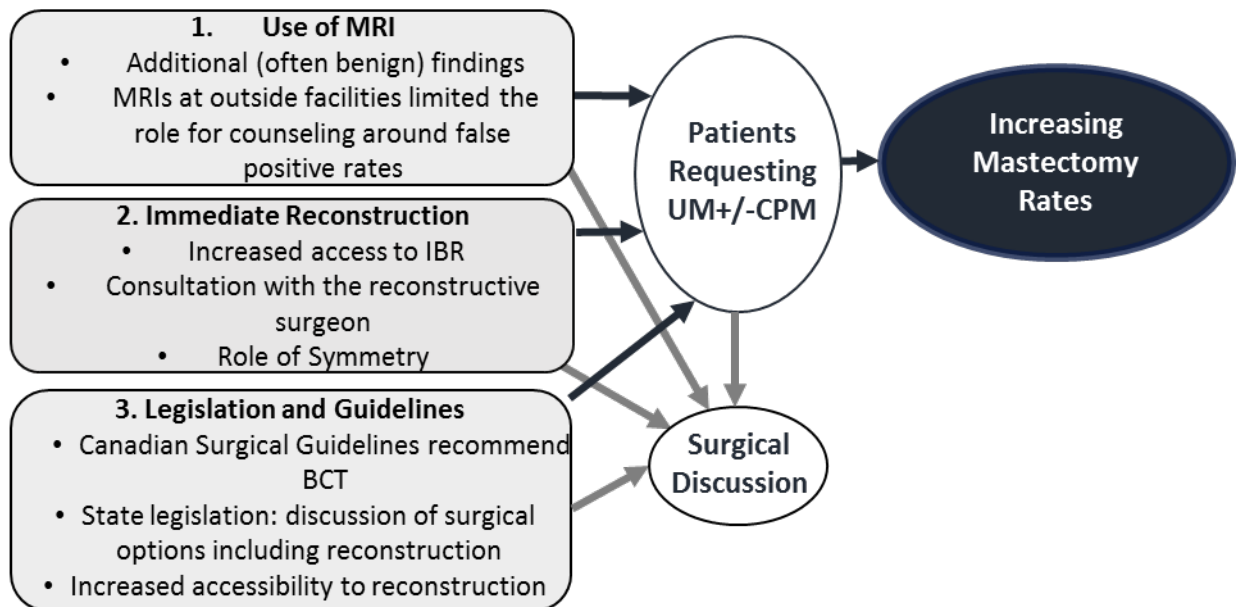
The surgeon's discussion of treatment options also appears to be shaped by legislation. Despite initial RCT trials demonstrating survival equivalence between UM and BCT, (Fisher et al., 1985a; Veronesi et al., 1981) BCT was unequally adopted across the U.S. (Harris, Hellman, & Kinne, 1986; Nattinger, Hoffmann, Shapiro, Gottlieb, & Goodwin, 1996). In attempts to increase uptake state laws, called 'alternative therapy laws', were implemented mandating surgeons describe all available treatment options. (Nayfield, Bongiovanni, Haenlein Alciati, Fisher, & Bergner, 1994; U.S. Department of Health and Human Services, 2008). 14 of the 20 states with such laws have statutes that explicitly require reconstruction be discussed in the initial consultation (Nayfield et al., 1994). In addition, the "Breast Cancer Patient Education Act of 2012" if passed, will federally mandate that surgeons inform women of their reconstructive options. Federal and state laws also require that insurance plans cover reconstruction and balancing procedures in women undergoing mastectomy. While Canada's universal health insurance covers reconstruction and balancing procedures in all women undergoing mastectomy, no provincial or federal laws exist governing the surgical discussion. Rather, Canadian surgeons are directed by surgical guidelines for the management of ESBC which state that "BCS and radiotherapy is generally recommended. In the absence of special reasons for selecting mastectomy" (Scarth et al., 2002). The differences in governance may be reflected in the differences in the Ontario and U.S. consultations. Ontario surgeons described both UM and BCT and frequently recommended BCT, in keeping with Canadian guidelines. In comparison U.S. surgeons often refrained from a direct recommendation but did present all treatment options including reconstruction and mastectomy in keeping with legislation.

While the decision for more extensive surgery ultimately resulted from the patient's choice, a number of external factors have the potential to shape the surgical discussion and influence this

decision-making process. MRI findings influenced a patient's choice for more extensive surgery; particularly when MRI use occurred without counseling around the potential benefits and shortcomings. Similarly, the availability of IBR and the role of the reconstruction consultation may impact the choice for UM+/-CPM. Legislation and guidelines shaped how surgeons discussed treatment options, resulting in a surgical discussion that consists of multiple options, without direct recommendations, leaving the final decision to the patient. A patient's surgical decision is often arrived at among a myriad of information in a relatively short period of time where the effects of MRI, reconstruction, and legislation may influence a woman's choice for mastectomy.

**Table 4: Surgeon Characteristics**

<i>Ontario Surgeons</i>		23 (n)	<i>United States Surgeons</i>		22 (n)
<b>Location of Practice</b>			<b>Location of Practice</b>		
Academic		11	Academic		11
Non-Academic		12	Non-Academic		11
<b>Length of Practice</b>			<b>Length of Practice</b>		
5-10		9	5-10		3
11-20		7	11-20		13
>20		7	>20		6
Median		15 years	Median		17 years
<b>Subspecialty Training</b>			<b>Subspecialty Training</b>		
None		8	None		9
Breast		4	Breast		0
Surgical Oncology		9	Surgical Oncology		13
<b>Gender</b>			<b>Gender</b>		
Female		11	Female		10
Male		12	Male		12

**Figure 9: A pictorial representation of the role of the health-care environment on increasing mastectomy rates**

**Table 5: Summary of the Key Concepts impacting the Surgical Consultation for ESBC**

Concept	Ontario Surgeons	U.S. Surgeons
<b>Mastectomy Rates</b>	<ul style="list-style-type: none"> <li>Increasing rates of Unilateral Mastectomy (UM) and UM+ Contralateral Prophylactic Mastectomy (CPM) in average-risk women with a unilateral Early-Stage Breast Cancer (ESBC)</li> <li>Patients requested CPM</li> </ul>	<ul style="list-style-type: none"> <li>Increasing rates of Unilateral Mastectomy (UM) and UM+ Contralateral Prophylactic Mastectomy (CPM) in average-risk women with a unilateral Early-Stage Breast Cancer (ESBC)</li> <li>Patients requested CPM</li> </ul>
<b>Surgical Recommendations</b>	<ul style="list-style-type: none"> <li>All surgeons irrespective of location (academic or community), length of practice, or extent of training described both Breast Conserving Therapy (BCT) and UM as equivalent treatment options for ESBC</li> </ul>	<ul style="list-style-type: none"> <li>All surgeons irrespective of location (academic or community), length of practice, or extent of training described both Breast Conserving Therapy (BCT) and UM as equivalent treatment options for ESBC</li> </ul>
<b>Legislation and Guidelines</b>	<ul style="list-style-type: none"> <li>Frequently Recommended BCT</li> <li>Canadian Surgical Guidelines were the basis of the recommendation</li> <li>Strongly discouraged and dissuaded patients from undergoing CPM; recommending they treat only the index cancer initially</li> </ul>	<ul style="list-style-type: none"> <li>Frequently No Recommendation was put forth. If directly asked some would recommend BCT</li> <li>Some States have legislation that mandates the discussion of both UM and BCT and often no recommendation was put forth</li> <li>Did not encourage but also did not advise strongly against CPM; often left to women's choice</li> </ul>
<b>Reconstruction</b>	<ul style="list-style-type: none"> <li>Introduced if patients were considering mastectomy</li> <li>No Legislative requirements mandating discussion of reconstruction</li> <li>Variable access to Immediate Breast Reconstruction (IBR); limited to academic and a few high volume community centers</li> </ul>	<ul style="list-style-type: none"> <li>Introduced at the initial consultation as part of the treatment options: BCT, UM, UM+IBR</li> <li>Some States have legislation mandating the discussion as part of the initial treatment options</li> <li>All surgeons had readily available access to IBR</li> <li>Access increased in part by Federal legislation mandating insurance coverage for reconstruction</li> </ul>
<b>MRI</b>	<ul style="list-style-type: none"> <li>Surgeons are the ordering physicians and decided upon MRI use</li> <li>Allowed surgeons to selectively use MRI and counsel patients about false positives/additional findings prior to undergoing MRI</li> </ul>	<ul style="list-style-type: none"> <li>MRI often completed prior to the patient seeing the surgeon and often at an outside facility</li> <li>Limited the surgeons ability for selective use MRI and to counsel patients about false positives/additional findings prior to undergoing MRI</li> </ul>



## Chapter 6 - Applying the Health-Belief Model: Understanding women's choice for mastectomy

This chapter represents the findings from the triangulation of both the patient and surgeon (Ontario and U.S.) interviews. While completing triangulation the findings the decision-making process for UM+/-CPM was reminiscent of the Health-Belief Model (a health-behaviour theory). The triangulated data was then applied to the framework of the Health-Belief Model and an understanding of women's choice for mastectomy is presented within this framework below. This chapter has been submitted to the British Medical Journal.

### **A Qualitative Study applying the Health-Belief Model - Understanding women's choice for mastectomy**(Covelli, Baxter, Fitch, & Wright, 2014c)

#### 6.1 Introduction

In 1990 the National Institute of Health released a consensus statement indicating, "breast conservation treatment is an appropriate method of primary therapy for the majority of women with Stage 1 and 2 disease (Early-Stage breast cancer, ESBC) and is preferable because it provides survival rates equivalent to total mastectomy while preserving the breast" (National Institute of Health, 1991). After the release of this statement the rates of unilateral mastectomy (UM) markedly decreased across a number of countries; the recommendation for breast conserving therapy (BCT) was widely adopted, with guidelines published in the United States (U.S.) Canada, England and Europe (Association of Breast Surgery at BASO, 2009; Carlson, Edge, & Theriault, 2001; de Koning et al., 1994; Gaudette et al., 2004; Harries et al., 1996; Lazovich et al., 1999; Scarth et al., 2002; Senkus et al., 2013). Recently a number of studies have documented the increasing use of both UM and contralateral prophylactic mastectomy (CPM) for the surgical treatment of unilateral ESBC, in women who are not at high-risk for developing a contralateral breast cancer (CBC) (Arrington et al., 2009; Ballinger et al., 2008; Canadian Institute for Health Information, 2012; Dragun et al., 2012a; Dragun et al., 2012b; Gomez et al., 2010; Jones et al., 2009; Katipamula et al., 2009; Mahmood et al., 2013; McGuire et al., 2009; Neuburger et al., 2013; Tuttle et al., 2007; Yao et al., 2010). Nation-wide studies from the United States using SEER registries and National Cancer Database, demonstrated a 10% rise in UM rate and over 150% rise CPM rates since 2000 across all age groups with unilateral ESBC (Mahmood et al., 2013; Tuttle et al., 2007; Yao et al., 2010). Similarly, nation-

wide studies from Canada and England have demonstrated a rise in the use of CPM in ESBC by 50% since the mid-2000s (Canadian Institute for Health Information, 2012; Neuburger et al., 2013). Importantly, this trend is not driven by changes in surgical management of women who are at increased risk of developing a CBC (having a positive BRCA1/2 mutation or two first degree family members diagnosed with breast or ovarian cancer) (Metcalf et al., 2014; Tuttle, Abbott, Arrington, & Rueth, 2010). There are no guidelines endorsing the use of CPM in non-high-risk women, because of a lack of survival benefit in this group (Lostumbo et al., 2010). While quantitative studies have demonstrated that more young, white, educated women of a higher socio-economic status are undergoing mastectomy; these studies do not describe **why** these women are choosing more extensive surgery (Benedict et al., 2001; Jones et al., 2009; Nekhlyudov et al., 2005; Tuttle et al., 2007; Yao et al., 2010). Other studies have demonstrated that the surgeon may be an independent predictive factor for receiving mastectomy, however the role of the surgeon has not yet be assessed in light of the increasing mastectomy rates (Arrington et al., 2009; Reitsamer et al., 2008). To understand the decision-making process that results in women undergoing mastectomy(ies), we conducted a qualitative study exploring the perspectives of patients who chose UM +/- CPM for ESBC and treating general surgeons. Many quantitative studies have identified demographic and pathological factors associated with the increase in mastectomy however this work moves to a deeper understanding of the patient's treatment decision-making process that results in the choice for mastectomy.

## 6.2 Methods

### 6.2.1 Design

This study was guided by a constructivist paradigm; i.e. to elucidate meanings and develop an understanding that is reflective of the given phenomenon (Guba & Lincoln, 2005; Weaver & Olson, 2006). Understanding the meaning both patients and surgeons give to a diagnosis of ESBC allowed us to appreciate the significance they have placed on the surgical decision-making process.

Grounded theory (GT) methodology was used to generate a theoretical understanding of the choice for mastectomy directly from the both the patients' and surgeons' decision-making experience. GT methodology approaches the data in a systematic manner which results in early analysis directing

focused data collection, producing a theoretical narrative describing those factors influencing surgical decision-making (Charmaz, 2000, 2009; Strauss & Corbin, 1990). By using both GT methodology and a constructivist paradigm, our research findings are transferable to similar settings where elements of the concepts and themes might be shared.

### 6.2.2 Sampling and Recruitment

For a detailed description of sampling and recruitment for both the patients and the surgeons please see previously published work (Covelli et al., 2014a; Covelli et al., 2014b). Women who were suitable candidates for breast conserving therapy (BCT) but underwent UM +/- CPM within the previous 9-12 months from their interview were identified from 5 prospective breast cancer databases at surgical centers in the Toronto Area, Ontario, Canada. Participants were purposively sampled from these databases ensuring they varied in age, ethnicity and that comparable numbers of women who underwent UM and UM+CPM were recruited from each center. Breast surgeons from across Ontario, Canada and the United States were also purposively sampled ensuring that they varied in location of practice (academic and community, urban and non-urban), length of practice, extent of training, and gender. Purposive sampling across representative groups allowed a wide range of motivations and perspectives on the surgical decision-making process for ESBC. Recruitment continued until we had achieved thematic saturation as indicated by data redundancy (Guest, 2006; Kuzel, 1992).

Initial contact with both the patients and the surgeons was made via a standardized letter inviting their participation, those interested returned a mail-in response form. Individuals who responded were contacted (by AMC) to explain the objectives of the study, the credentials of the researchers and to answer any questions. Direct contact occurred at the time of the pre-arranged interview. The study was reviewed and approved by the institutional Ethics Review Boards at each centre.

### 6.2.3 Data Collection

Tenets of GT include: simultaneous data collection and analysis, constructing codes from data analysis, and the constant comparison of the evolving categories (Charmaz, 2009; Strauss & Corbin, 1990). GT methodology directed the generation of the interview guides, data collection and data analysis (Charmaz, 2009; Lingard et al., 2008; McCann & Clarke, 2002). From a systematic

literature review a conceptual framework was developed to inform the interview questions. The interview guides were developed by three individuals (AMC, MF and FCW) two of whom are experts in qualitative research (MF and FCW). Four pilot interviews for both the patients and the surgeons were audio-recorded, transcribed verbatim, and then discussed among the research team (AMC, MF, and FCW). The interview guides were then adjusted to ensure all areas of interest were addressed. One-on-one interviews were audio-taped and performed by a single interviewer (AMC under the guidance of FCW); field notes were made after the completion of the interview. Non-participants were not present during the interviews. Patient interviews were conducted in either a private room at the participant's surgical center or a location of the participant's choice. Surgeon interviews were conducted over the telephone. Each participant was interviewed once, repeat interviews were not conducted. Saturation occurred when identified concepts began to recur and no new concepts emerged from the data (Guest, 2006; Kuzel, 1992). Saturation was reached after 29 patient and 45 surgeon interviews.

#### 6.2.4 Data Analysis

The interviews were transcribed verbatim and GT methodology was used to analyze the data, the data was then managed using Excel spreadsheets. Interviews were coded independently by two investigators (AMC and FCW), and findings were discussed with the entire research team (AMC, NNB, MIF and FCW). Simultaneous data collection and analysis generated a coding schema reflecting unique ideas (Charmaz, 2000, 2009; Lingard et al., 2008). Constant comparative analysis of the schema allowed similar concepts to be grouped together into larger categories (Charmaz, 2000, 2009; McCann & Clarke, 2002). After the independent analysis of the patient and surgeon interviews, triangulation across data sources was completed. Triangulation allowed for the comparison and contrast of the concepts derived from the patient, Ontario surgeon, and U.S. surgeon interviews. Combining the data sets provided a broader depth and scope of the phenomenon (Farmer et al., 2006). Through constant comparative analysis of the triangulated categories, along with discussion among the research team, it became apparent that our developing theory was reflective of the Health-Belief Model, a conceptual framework.

#### **6.2.4.1 Framework:**

The Health-Belief Model (HBM) is one of the most widely used and validated conceptual frameworks to explain health-related behaviours (Janz & Becker, 1984; Rosenstock, 1974). The HBM has been useful in describing sick role behaviour; the “activity undertaken by those who consider themselves ill, for the purpose of getting well” (Becker, 1974; Janz & Becker, 1984). The original 4 concepts of the HBM are: 1. perceived susceptibility: the subjective perception of the risk of recurrence of the illness or vulnerability to the diseases (Becker, 1974), 2. perceived severity: the perception of the seriousness of leaving an illness untreated (Champion & Skinner, 2008), 3. perceived benefits: the perception that the behaviour is potentially beneficial in reducing the perceived susceptibility and/or severity (Becker, 1974; Rosenstock, 1974), 4. perceived barriers: perception of the impediments and/or negative aspects related to undertaking the health-related behaviour (Champion & Skinner, 2008; Rosenstock, 1974). An additional concept related to the HBM is self-efficacy, the individual feels competent to overcome the perceived barriers and successfully undertake the health-related behaviour (Rosenstock, Stretcher, & Becker, 1988) (Rosenstock et al., 1988).

Completing focused coding using the concepts of the HBM, our triangulated data was iteratively explored and refined into larger themes driving the research toward theory construction. Theoretical coding resulted in theory generation which expands upon the HBM, applying it to the understanding of the surgical decision-making process in ESBC.

## **6.3 Results**

### **6.3.1 Participants and Interviews**

Interviews were conducted with 29 patients and 45 surgeons. Participant characteristics are included in Tables 2 and 3 (above). 15 patients underwent UM and 14 participants underwent UM+CPM. All patients had ESBC. Median interview time for the patient’s interview was 71 minutes (range 50-91). 23 surgeons were from Ontario and 22 were from the U.S. Median interview time was 43 minutes (range 26-93). All participants consented to participation prior to the onset of the interview.

To illustrate our research findings we have selected demonstrative patient and surgeon quotations. The quotations are representative of both typical responses and the range of views expressed. The examples are labeled by participant number and population (Patient, Ontario surgeon, U.S. surgeon).

## 6.3.2 Themes

### 6.3.2.1 Perceived Susceptibility

**Patients:** Patients perceived that they were highly susceptible to, and overestimated, the potential negative sequelae of breast cancer including local recurrence in the ipsilateral breast, development of a contralateral breast cancer (CBC), and distant metastasis. Women expressed their fears of this susceptibility with comments such as:

*“The recurrence is huge. The recurrence thing scares me a lot.” (P2)*

*“The high probability of recurrence... ‘is it going to come back’ (P9)*

*“I didn’t want to have this constant cloud over my head. I wasn’t sure, you know, is it further ? Is it elsewhere?. Then six months, come back again.” (P10)*

Along with the fear of recurrence many patients also voiced concerns about the cancer’s potential to ‘spread’, to the non-cancerous breast (development of a CBC).

*“I would have always thought in the back of my mind it might come back and could it grow in the other breast as well?” (P19)*

*“If you get another tumour in your other breast it’s a brand new cancer. I don’t have it in me to listen to in three years say, ‘I’m really sorry but it spread again’. I could not ever think about being cut up bit by bit. Going through this three years, five year, eight years, ten years” (P28)*

*“I knew that I would be every six months back at the hospital because the first place it goes to is the other breast”. (P26)*

*“My fear was that, I wouldn’t want to wake up every morning and think, ‘Oh, did it go there yet? Oh, did it travel there?’, because I know that’s what I would have done” (P8)*

Participants also described the potential ‘spread’ of their cancer as distant metastasis.

*“I’m just afraid that it might spread to other parts of my body. You know, it could be anywhere” (P6).*

*“Well, what if? What if it spreads? What if it comes back?” (P15)*

*“It could come back. It generally does not come back in the same place. It may come back in bone marrow.” (P16)*

*“My big fear was where was this cancer going in my body? I was sure that my body was rampaged by cancer because I had breast cancer.” (P2)*

Patients’ perceived susceptibility to recurrence and ‘spread’ resulted from their previous experiences. This included events that occurred while diagnosing their own cancer, as well as previous experiences with family and/or friends who had breast cancer. Many of the patients in our study shared that they had previously lived through a cancer experience with family or friends. These experiences were often negative, with our participants having witnessed recurrence and metastasis.

*“She (my mother) died in 1984 of metastasized breast cancer to her liver” (P 27)*

*“She (my aunt) had a lumpectomy originally and the cancer came back.” (P25)*

*“One of the women I made very close friends with. She basically had gone through a mastectomy, before I did. She knew what it was all about and she was going in for her second one. She said she needed to have another mastectomy.” (P8)*

*“I spoke to friends of friends who were in the health care system, and I also spoke to other women who had, had breast cancer. The thing that stands out in my mind are the women who did not choose to have mastectomies who regretted the decisions later. I’ve spoken to quite a few people like that” (P9)*

*“Women would tell you about how they’d had a lumpectomy and then six months it came back and then it’s somewhere else, you know?” (P10)*

Some patients also described complexities with their diagnosis which resulted in further imaging, usually MRI, and subsequent biopsies. MRI findings sometimes demonstrated additional disease which led to concerns about the extent of their cancer and the potential for recurrence or ‘further spread’.

*“The mammogram did not discover the cancer. I had the mammogram, I had the second shot and I had clinical exams. Nobody knew it was cancer. Only the MRI discovered it, so that means it could happen anytime again” (P4)*

*“They also found in the breast MRI that I had an unspecified lump.” (P9) “*

*“The mammogram showed up nothing.. The MRI showed up a 3.75 centimeter tumour. It was very frustrating. I had the three months going back and forth to people trying to say that, ‘There’s something here’” (P26)*

*“In the MRI they found another mass in the other (the other) breast (which they missed before” (P27)*

**Surgeons:** When surgeons discussed the risk of local recurrence, they stated that risk was low and recurrence was only marginally elevated with BCT compared to UM.

*“There’s minimal local recurrence risk.” (ON-2)*

*“Let’s say the recurrence rate is 8%. I say, ‘You know what? On the other hand, that is 90% that you will not have recurrence. If you do recur, fine, we’ll do a mastectomy at that point. That’s not really going to influence your survival. But if we did a mastectomy up front, that means 92% of the time, it was unnecessary.” (US-2)*

*“The recurrence rates was 8%.” (US-15)*

*“The local recurrence rate isn’t necessarily improved with mastectomy as compared to lumpectomy as long as margins are clear, followed by radiation. The statistics say that they are the same.” (ON-7)*

Similar to the discussion on ipsilateral recurrence, surgeons described the risk of developing a CBC as a low.

*“In the next 30 years you have a 10% chance of getting a cancer on the other breast.” (US-18)*

*“Your risk on the other side is much less than what you think. It’s ½%-1% per year up to a maximum of 5-8% in your lifetime.” (ON-11)*

*“There are quoted figures that say 1% per year. (ON-3)*

*“There is a 6-10% chance that you might get another breast cancer in that other breast in your lifetime. Well I think 90% chance that you won’t get it sounds really high” (US-9)*

*“The risk for contralateral cancer. That risk is pretty much the same or just slightly higher than the average population risk. I quote 12-15% contralateral breast cancer to make them aware that the risk isn’t that much higher on the other side.” (US-14)*

Surgeons also tried to disentangle the concepts of local recurrence and distant metastasis, stating that metastatic spread is not impacted by local surgical management, and that the choice for more extensive surgery does not reduce the risk of distant metastasis.



*“Somebody might have seen somebody else choose a lumpectomy and they died. Well, they died from metastatic breast cancer. Lumpectomy had nothing to do with it. I can’t get them beyond that differentiation” (US-2)*

*“The most dangerous thing about breast cancer is if it spreads. So, what we do with the breast is not make the absolute determination of their prognosis. They have breast cancer already that may be a metastases that we are dealing with in the future rather than a tumour in the breast itself” (US-10)*

*“The risk to you is not from having a new breast cancer. The risk to you is that the cancer you already have is spread.” (US-18)*

*“I’m also careful to say to them that there is difference between local recurrence at the breast and distant failure with metastasis”. (US-12)*

*“We talk about the fact that people die from metastatic disease, and not from local recurrence of the breast” (ON-10)*

Additionally, surgeons stated that a CBC could develop independently of the initial cancer.

*“They think that a breast cancer is going to spread to the other breast. That’s a huge misunderstanding” (US-3).*

*“Removing the side has no relation to, you know, recurrence (locally or distally) of the side they’ve had treated.” (ON-17).*

Many of the surgeons indicated that they were aware of the patients’ perception of an increased susceptibility to recurrence and metastasis stating:

*“I think they really estimate risk much higher than what it is. (ON-6)*

*“There is a 6-10% chance that you might get another breast cancer in that other breast in your lifetime. She thought that 10% was huge. You know, I would think 10% is low and 90% is really high.” (US-9)*

*“It’s a very, very exaggerated belief that they will get cancer on the other side.” (US-3)*

*“You can quote them a risk that is less than a risk of someone walking down the street of ever having another breast cancer and it all sounds too much to them.” (ON-21)*

Surgeons were also aware of the role of MRI, and personal experience in shaping patients’ perceived susceptibility to the negative sequelae of ESBC.

*“As soon as you have an MRI on somebody who has a breast cancer, and you find something else on the other breast even thought to be benign, that’s still very anxiety-provoking” (US-7)*

*“There were those cases of patients who got a breast MRI and a whole bunch of stuff showed up...most of that stuff is nothing anyway, but it’s enough to alarm some patients” (US-19)*

*“I think they can add to anxiety. The MRI report never says that there is nothing anywhere in the breast. An MRI sees everything and our radiologist of course describes everything they see. When a lay person reads that description, it can be very frightening” (ON-21)*

*“Patients say ‘My mom had a lumpectomy. Cancer came back five years later’ and they associate those things. I can’t get beyond sometimes some very strong, emotional aspects.” (US-2)*

*“Women who were not questioning the need for mastectomy might come back to me and say, ‘Hey. But I talked to women who had breast cancer ten years ago and it came back. What are my odds?’” (US-11)*

*“They know other people who have had breast cancer who then developed another breast cancer on the other side. They say, ‘I’ve seen it happen. I don’t want it to happen to me’”. (US-1)*

*“The experience of a friend of theirs or some other family member who had breast cancer and then had recurrence.” (ON-10)*

*“It’s a personal experience where either somebody has a recurrence or perhaps a less than favorable outcome and they think it’s going to impact on that outcome.” (ON-20)*

However, despite being aware of the role that the previous cancer experience had on shaping the patients’ perceptions, surgeons frequently did not report discussing these experiences and their potential influence on the decision-making process with the patient.

### **6.3.2.2 Perceived Severity**

**Patients:** Patients also overestimated the severity associated with the diagnosis of non-high-risk ESBC. All patients felt that they were at substantial risk of dying from their disease as evidenced by comments such as:

*“I believed that cancer will not have any survival. The patients who have cancer – there is no treatment and the survival rate is very low.” (P3)*

*“I know that I had cancer. I know there’s a chance that I could have cancer again. I really don’t want to die of cancer because I know it’s not a nice death” (P2)*

*“My mother died from it. So, I immediately jumped to the conclusion that, that could possibly be my outcome as well.” (P15)*

Much like their perceived susceptibility, patients’ perceived severity was voiced with fear.

*“I was so afraid I’m sure I was dying. I was sure I was dying.” (P2)*

*“The first thing is ‘you’re going to die.’ I mean, I came home to my husband and said ‘I’m going to die’” (P13)*

It was frequently, a previous experience of a loved one who died from cancer that often shaped our patients’ perception of the severity of ESBC.

*“Mom died from that. She was 44. She had surgery every month probably because the – they didn’t offer her mastectomy. It was metastatic all over.” (P28)*

*“They did a lumpectomy. Unfortunately, the second time she found a tumour in the same breast and it was cancerous. Within two years, she had metastases to bone and lung and after two years she died. She was one of my best friends.” (P3)*

**Surgeons:** In contrast to the patients’ discussion of their perceived mortality, surgeons emphasized the curability of ESBC.

*“90-92% of women in the United State diagnosed with breast cancer go on to survive their disease.” (US-5).*

*“They (patients) still manage to survive and do well.” (US-11)*

*“An average breast cancer, she has a 10% risk of dying with the breast cancer we know. She has a 10% risk of having the contralateral side (having a breast cancer in the future) and only a 3% chance of dying of that cancer.” (ON-2)*

*“In the next 30 years you have a 10% chance of getting a cancer on the other breast. So, that’s 1 in 10. Of those people, 1 in 10 may die from that cancer. So 1% chance. But remember, that’s before age 88. Between now and then you have a 40% to 50% chance of dying (from something else).” (US-16)*

However, many surgeons recognized the role of previous cancer experience in shaping patients’ perceptions of the severity of ESBC. Sharing statements such as

*“Dr., I watched my mother die. I’m not going through that. I don’t need these breasts”. (US-15)*

*“Everybody has/knows of a horror story....somebody had recurrence and died, it was a terrible ordeal for that patient so they just say, take them off. (US-14)”*

*“My patient wants bilateral mastectomies, her mother had a mastectomy and radiation and then recurrence with metastasis and saw her have a terrible quality of life and die of the disease....In her mind those are really in the forefront” (ON-6)*

*“‘I want a mastectomy’... Their mom died of breast cancer at 50 even though it’s not high, high risk for them or something has happened to them in their life that has really freaked them out about breast cancer.” (ON-17)*

### 6.3.2.3 Perceived Benefit

**Patients:** Many patients perceived that the principal benefit of undergoing more extensive surgery was to decrease their risk of a local recurrence and distant metastasis as well as the development of a CBC. Patients expressed that choosing BCT would have resulted in a recurrence of their breast cancer whereas undergoing mastectomy eliminated this likelihood.

*“I had already made up my mind to do the mastectomy because I don’t want to live in the shadow of recurrence.” (P7)*

*“I don’t want any worries of recurrence. That’s when I thought it is better just to remove it.” (P6)*

*“Mastectomy, 100% because I didn’t want any risk of recurrence (at least in that breast.” (P13)*

*“Get rid of it (re. mastectomy). Let’s go for it. The thought of recurrence.” (P17)*

*“By having a mastectomy suddenly I would reduce my chances of recurrence by 50%” (P4).*

*“I know that even if one cell is left there, it is a risk factor for recurrence” (P3)*

Many patients chose UM with CPM as they felt it prevented the ‘spread’ of their cancer to both the contralateral breast as well as to distant organs.

*“I thought, well if I have two mastectomies, there’s no way I’m can ever get breast cancer again.” (P2)*

*“I’m just thinking if there’s breast tissue there it’s coming back, you know? So we discussed having the bilateral.” (P1)*

*“I wanted to have a mastectomy on the opposite side because I don’t want to face this problem again - even one percent.” (P3)*

*“It would be better for me if they were both gone and I wouldn’t be able to get cancer in the other breast.” (P9)*

Most importantly, many patients felt they would definitively improve their survival if they underwent UM+/-CPM .

*“You can’t guarantee I’m going to be 100% cured, but I’ll take the 95-99% that your confident that if you remove it (if I have a mastectomy), that’s a high probability. I wanted to take the course of action that was going to give me the best chance of survival... I really didn’t consider any other option actually because I wanted to live. (P15)*

*“To preserve (my breast) ...To me, it’s not important as preserving my life. Maybe I should put it this way. Yeah. My first priority is to live long, right?” (P7)*

*“Take these two breasts off. Now, that would have been not maybe the right decision but that didn’t scare me. I would be willing to take that risk so that I didn’t die from breast cancer at the age of 63” (P18)*

*“I was quite clear in my end objective, which longevity of life was. Whatever was going to give me the best outcome for that, I was more focused on that than I was on breast conservation” (P29)*

Some patients also discussed the benefit of avoiding future surveillance of the opposite breast by choosing UM+CPM.

*“I don’t want to be here every six months. I had to have an MRI every six months, and I didn’t want to do that.” (P26)*

*“Only the MRI discovered it - so that means it could happen anytime again. Unfortunately, I can’t get an MRI now even with this experience now on a regular basis. So, these were all the factors that came into it (choice for mastectomy)” (P4).*

*“On the opposite side, they found a spot with the mammogram and had to go through this MRI. She said, “Maybe we’ll just do a biopsy of it”. I thought, I can’t do this every year! If I ever do reconstruction, you know, I want to get off my opposite breast too” (P13).*

This was expressed predominately by those patients who had required further imaging and work-up to obtain their diagnosis. “In addition to reducing the fears of the associated susceptibility and severity of ESBC, some patients chose CPM for the additional benefit of symmetry and balance offered by having both breasts removed.

*“I need to have it look symmetrical versus saving a breast for whatever have you. I knew that long-term I’d worry about cancer getting into my right breast.” (P19)*

*“I had a balance problem because I had one breast and one no-breast. So it just made sense at that point to get actually get rid of both of them.” (P17)*

*“My choice would be flat (re CPM), because that also give me the peace of mind as well as the matching symmetry” (P14).*

*“So I had the double mastectomy, reconstructive with expanders. I much preferred, wipe the slate clean. Do whatever you have to do to fix them up. Try to get them as normal as possible so I can walk by the mirror so I can feel good about myself so when I take off my clothes. Oh! It wasn't so bad.’ I wanted to be as even as I possibly could. Just get me back to normal.” (P8)*

**Surgeons:** In contrast to the benefits perceived by the patients, all the surgeons described no significant decrease in either the susceptibility or severity of ESBC by undergoing UM+/-CPM . Both U.S. and Ontario surgeons described that there was no guarantee of preventing local recurrence even in the setting of a mastectomy; making comments such as:

*“There is this notion that if you have a mastectomy the cancer will definitely not come back, they have no risk of local recurrence, which is wrong. They are quite surprised when I tell them that there is always a risk of local recurrence even after mastectomy. I think there is this belief that doing a mastectomy will protect them from not only recurrence, but make them live longer.”(ON-6)*

*“Because the cancer and recurrence, that common belief that mastectomy is superior” (US-2)*

*“There are a group of women who really believe that by having more extensive surgery, it will reduce their risk of recurrence and death.” (ON-19)*

Surgeons described the likelihood of an average-risk patient with ESBC developing a CBC as very small, and therefore the benefit of undergoing prophylactic mastectomy in this population as nearly negligible.

*“If somebody has no risk factors, general population, then their risk of contralateral disease is 10-12%. So I can still give them 97% (they won't get a contralateral cancer), but it's only going to bring them down as 2% and 3%. So, that's only like a 5% or 6% benefits. So, that is a lot of surgery and undoing of natural tissues for that small of a risk.” (ON-4)*

*“They always say, “I don't ever want to have to go through this again”. They feel that if they take both the breasts off there is something conclusive about that they will never get breast cancer again.” (US-10)*

*“A risk of a new primary on the prophylactic side is 1-2% lifetime risk and ‘your chance right now of ever getting a cancer again in either breast is only 10%, next you’re going to remove your breast for a possible 6-8% difference and we can reduce your risk and half by your anti-estrogen therapy’. It’s a very, very exaggerated belief that they will get cancer on the other side.” (US-3)*

*“The issues of contralateral prophylactic mastectomy. Often times they come in wanting a mastectomy. But when you explore more with them, what they really want is to be disease-free. So, if I tell them that you can achieve that either way (BCT vs UM)” (ON-12)*

All surgeons reported describing to patients no survival advantage offered by undergoing UM+/-CPM rather than BCT.

*“I will make sure that they know that the chance of them dying from the breast cancer, the chance of being cured from it, are going to be exactly the same between the two therapies (BCT and UM).” (ON-8)*

*“But overall, their survival – how long a woman lives is not affected by that choice of lumpectomy or mastectomy (US-12)*

*“The long-term survival is no better with a mastectomy. I translate. I say, “In other words, you’re not going to live any longer if I remove your breasts. Some patients are surprised by that”. (US-20)*

*“They will feel most comfortable with bilateral mastectomy even though they are candidates for a unilateral lumpectomy. I try to make it very clear that it’s not going to change their overall survival” (US-14)*

*“I just say ‘you’re going to live the same period of time no matter what option you choose’”. (ON-16)*

*“We talk about that it’s (CPM) not going to make a difference in their survival. So I think I emphasize that point to them.” (ON-6)*

Despite describing no substantial decrease in ipsilateral recurrence and CBC, nor notable survival advantage, surgeons recognized patients over-estimated the benefits of UM+/-CPM.

*“They really estimate risk to be much higher than what it is. There is this notion that if you have a mastectomy the cancer will definitely not come back, they have no risk of local recurrence, which is wrong. They are quite surprised when I tell them that there is always a risk of local recurrence even after mastectomy. I think there is this belief that doing a mastectomy will protect them from not only recurrence, but make them live longer.”(ON-6)*

*“They always say, “I don’t ever want to have to go through this again”. They feel that if they take both the breasts off there is something conclusive about that they will never get breast cancer again.” (US-10).*

*“What drives women to choose a mastectomy, is that they think it leads to better survival.” (US-2)*

*“Most patients think if you don’t go big, you are compromising survival. So they just think by going big, they will do better. I think that’s what they struggle with and try and understand that that’s not really truly the case” (ON-2)*

*“Some of it is the fear, too. When you’re dealing with a diagnosis of breast cancer there is a thought of just removing the cancer or the breast as to not have to deal with this again. I do think it is a perception of some women that, ‘If I do a mastectomy’ (a misconception) that, ‘I may do better’.” (US-12)*

*“They think that their chance of being alive ten years from now or twenty years or now is going to be better if they have a bilateral mastectomy”. (ON-3)*

*“You’re doing more surgery so that you don’t have to worry about the other breast. If you don’t do a contralateral mastectomy, then everything that happened in the breast where you had your cancer can happen in the other breast too!” (US-4)*

#### **6.3.2.4 Perceived Barriers**

**Patients:** In contrast to the perceived benefits, patients greatly underestimated the impact of the barriers, including the potentially negative outcomes of undergoing more extensive surgery. Complications of the surgical procedure were often not attended to by the patients at the time of their decision-making and very few reported considering the potential side-effects.

*“I was told that there is a chance after mastectomy that you could developed nerve pain. I minimized that part – I ignored it. That, of course, is what happened” (P4)*

In contrast, many patients in our study reported suffering side-effects after undergoing a mastectomy. These included chronic nerve pain, changes in skin sensation and concerns with body image.

*“After I had a mastectomy) and I saw myself in the mirror. I don’t like my physical appearance it made me upset.” (P3).*

*“I don’t want my husband to see me. I can’t show my husband my scar. I never show him my scars, after this surgery he’s never seen my breasts.” (P11)*



*“You have no nipple so all sensitivity is gone and everything. It doesn’t – I don’t think it looks anywhere like a real breast... With the clothes on, fine, you know? But nobody sees the other side at the end of the day when you take off your mask.” (P12)*

*“I was swimmer. I can’t swim anymore. It feels really, really strange. I don’t know if I can’t swim because of weight that is one side or I can’t swim because I don’t feel this arm that much.” (P23)*

While no patient described any difficulty in accessing a surgeon for their work-up and treatment of ESBC, some patients described receiving opposition from their surgeon about their surgical choice; particularly for those women who chose UM+CPM.

*“Actually, I wanted a prophylactic mastectomy as well. The surgeon really cautioned me against it; really didn’t want me to do that at all. The surgeon said, ‘It’s not going to change the outcome. It’s not going to make you live longer’” (P13)*

*“(re CPM) We actually butted heads. We went back and forth. I was challenging my surgeon, “What do you mean? But everybody’s doing it and if they are doing it, it must make sense and listen it makes sense to me.” (P2)*

Many women who had elected to undergo more extensive surgery described diminishing this barrier by finding support for this decision from friends, family and the broader breast cancer community.

*“He (husband) walked me through the cancer and oh, my God. There couldn’t be anybody better than him. As long as I lived, he didn’t care what I did.” (P18)*

*“With my husband. He supported the decision. But I said to him, “You know what? This is what I want to do.” He said, “Do what you got to do.” So, I was very lucky in that way” (P25)*

*“I only have three friends. All of them are nurses. They agreed with me with my decision and supported my decision.” (P3)*

*“When I came back to the doctor, I had met somebody in the cafeteria. She had already been through that. Because I wasn’t familiar with any of this, she was actually my mentor. I knew there was somebody I could call that was going through this and had been going through this before and know what it was all about and going through it again”. (P8)*

*“Our next door neighbor, his girlfriend, she was six months ahead of me. She was going for breast cancer treatment at the time. She had, had her surgery and as going through all the treatments. She was one of the first people I called.” (P20)*

*“I had been through friends of friends. They hooked me up with friends of theirs who had breast cancer. It’s a very tight-knit community out there of breast cancer survivors. As soon*

*as you hear a friend has breast cancer, then they kind of connect you someone that they knew that had a friend who had breast cancer. Immediately, I had three women who I knew through friends of friends of friends who supported me through this whole endeavor.” (P19)*

**Surgeons:** Surgeons often described encouraging women to undergo less extensive surgery, frequently recommending BCT.

*“I reiterate that the recommended procedure is to have the lumpectomy. If they can have a lumpectomy, that’s what most women would choose” (ON-2).*

*“They want a mastectomy. For early stage breast cancer, I usually try to talk them out of that. I try to explore why they want a mastectomy” (ON-10)*

*“I focus tremendously on trying to accomplish breast conservation” (US-13)*

*“I really strongly encourage breast conserving therapy assuming that they are appropriate candidates” (US-2)*

Similarly, surgeons often discouraged women from undergoing UM+CPM, encouraging women to treat solely their current cancer.

*“With the bilateral ones, if they have just had it straight-forward, no family history, small malignancy and they want both sides off – I try to talk them out of it. “The cancer you have to worry about today is the cancer you have, not the cancer that you might get down the road”.(ON-3)*

*“Usually, I don’t do the prophylactic. Like, I can’t think of a situation where I’ve done it at the same time. But usually I’ll tell them, “Okay. Let’s deal with the cancer first and we are going to see if you need chemotherapy.” (ON-1)*

*“If she asks me for the opposite side, I’ll point that out to her and say, you know, were not accomplishing much by removing your other breast and I don’t recommend it. Let’s just worry about the problem we have now and if down the road you feel that way we can do the other side.” ON-2*

*I explain to them that it’s unlikely to be necessary, but then I do let them make that decision. I say, “You know, if you want me to do it and you’re not at prohibitive risk to try it, you know, it’s something that I’m willing to do as long as you understand the risks involved and have a reasonable reason for why.” (US-1)*

*“My nurse practitioner...she would go in and see the patient. She’d go out and say, ‘Well, she looks like great candidate for breast conservation but she wants a mastectomy and she wants a bilateral mastectomy, but I know you can talk her out of it.’ So, she would challenge me, unless of course she thought they were really good indications for that. I would go in and talk to them. But I always tell them, you know, it’s ultimately their decision and that’s fine but I feel like they have to have all the information before making that final decision “(US-9)*

A perceived barrier of surgical decision-making is the potential risks associated with the treatment options. While post-operative complications often went unconsidered by the patients, they were always routinely described by the surgeons as part of the surgical consultation, to ensure that patients were fully informed of both the surgical risks and benefits. Surgeons discussed the potential for chronic pain as well as the potential cosmetic and lifestyle changes that can be associated with UM+/-CPM.

*“You understand that 60% of women who get mastectomy will have chronic pain. You get that. You understand the potential risks, pros and cons” (US-11)*

*“I do talk a little bit about the length of the procedure, the complications, and the overall recovery with those two approaches (BCT and UM). If you have a double mastectomy, you’re going to have more complications. You’re going to have a longer recovery. You’ll have drains and tubes and all these potential complications.” (US-6)*

*“From the point of view from the mastectomy, I do tell them that there will be a straight line across and it will be flat and the scar itself may become wider.” (ON-9)*

*“A lot of times I would see that even though at the beginning it may have been a knee-jerk reaction to have the mastectomy, after awhile, you know, because of the body image issues, that they do actually suffer.” (ON-11)*

*“Realize even though it’s nipple-sparing, I try to reinforce it. There’s no sensation here, the nipple is just cosmetic.” (US-17)”*

## 6.4 Discussion

### 6.4.1 Principle Findings

The HBM states that whether a health-related behaviour is undertaken is determined by the magnitude of the threat of the illness (which is subjectively perceived, rather than objective risk), weighed against the potential benefits and barriers of undertaking that behaviour (Becker, 1974). Applying the concepts of the HBM to this research demonstrated that patient’s greatly overestimated their perceived threat. Women believed they were highly susceptible to the sequelae of ESBC, including ipsilateral recurrence, distant metastasis and development of a CBC. Women perceived that the severity of ESBC was substantial, and that they had a high likelihood of dying from their disease. Furthermore, patients believed there was a direct relationship between leaving breast tissue

in the cancerous breast and the development of more extensive disease, subsequently resulting in death. Women's perceptions were shaped by their previous cancer experiences, both by the difficulties some women encountered during the work-up of their own diagnosis, as well as family and friends who had suffered recurrence, metastasis and/or death due to breast cancer.

The over-estimation of our patients' perceived threat becomes apparent when contrasted with the information provided by our surgeons. Both the potential susceptibility and severity of ESBC were discussed by the surgeons in terms of objective risk. Surgeons stated the risks of recurrence and contralateral cancer are low in average-risk ESBC, and that the local treatment of the primary tumour does not impact the development of a CBC nor metastasis; countering the patients' perceptions that remnant breast tissue leads to more extensive disease. Similarly, surgeons described the high survivability of ESBC rather than the high mortality, as perceived by our patients.

Perceived susceptibility and severity is not sufficient for producing a health-related behaviour, an individual must also weigh this perceived threat against both benefits and barriers (costs) of undergoing that behaviour (Rosenstock, 1974). For our patients, the potential benefits of undergoing mastectomy greatly outweighed the potential costs. By choosing to undergo UM+/-CPM our patients believed they would eliminate all likelihood of recurrence, CBC, metastasis and subsequent death. Women who chose CPM also described the added benefits of avoiding surveillance in the contralateral breast, and improved symmetry. In contrast, patients underestimated the costs/barriers of undergoing mastectomy(ies). While many of our patients suffered the complications of undergoing mastectomy(ies), none of our patients considered the potential for these complications in their decision-making process. Surgeons always described the potential complications of all the surgical options.

The only barrier perceived by our patients was the resistance received from their surgeons around the decision to undergo UM+CPM. Patients minimized this barrier through support from the breast cancer community, and their own self-efficacy, ultimately facilitating their choice for UM+/-CPM.

### 6.4.2 Results in Context

Multiple long-term studies have demonstrated that there is no difference in distant metastasis or survival when undergoing either BCT (including radiation) or UM as treatment for unilateral ESBC

(Fisher et al., 2002; Hwang, Lichtensztajn, Gomez, Fowble, & Clarke, 2013; Van Dongen et al., 2000; Veronesi et al., 2002). In terms of ipsilateral recurrence, older studies demonstrated a slightly higher rate of recurrence with BCT as compared to UM (Jacobson et al., 1995; Van Dongen et al., 2000; Veronesi et al., 2002), but with current adjuvant chemo- and hormonal therapy the rates of recurrence are approximately equivalent (Forbes et al., 2008; Nguyen et al., 2008). CPM has not demonstrated a survival benefit in women with a unilateral ESBC who are at average-risk of developing a CBC (Lostumbo et al., 2010). While undergoing CPM does decrease the rate of CBC, the risk of developing CBC in non-high-risk ESBC is very low, approximately 0.5% per year with a maximum lifetime risk of 10%, or less in the setting of adjuvant therapy (Nichols et al., 2011; Rutqvist et al., 1991; Schaapveld et al., 2008). Importantly, in women who are not a high risk of developing a CBC, the risk of distant metastasis and death from the initial breast cancer outweighs the risk of developing a CBC, thus negating the potential benefits of undergoing a CPM (Rosen et al., 1993). In contrast, it has been demonstrated that undergoing CPM doubles the risk of post-operative mastectomy complications including infection, bleeding and re-operation in the non-cancerous breast (Goldflam et al., 2004; Miller et al., 2013; Osman et al., 2013). Given the potential for these complications and lack of demonstrable *survival* benefit, it is not immediately apparent what might be motivating the choice for more extensive surgery; however, applying the HBM demonstrates why the patients in our study decided to undergo UM+/-CPM.

The choice for mastectomy was based on our patients' overwhelming perceptions about their susceptibility to negative sequelae and severity of their ESBC (FIGURE 10). These perceptions were based on women's previous negative cancer experiences, which were discussed with notable apprehension and fear. Studies examining the HBM and other decision-making models have demonstrated that previous experience and fear shape an individual's perception of their susceptibility and disease severity (Becker, 1974; Kirscht, 1974b; Prentince-Dunn & Rogers, 1986; Witte, 1992). More recent literature has demonstrated that in a healthy population, having a fear of cancer results in an overestimation of mortality due to cancer (Del Castillo, Godoy-Izquierdo, Vazquez, & Godoy, 2011). It has also been reported that knowing someone with cancer increases an individual's fear around receiving the diagnosis of cancer (Katz et al., 1987), and having a family member with cancer has the greatest influence on shaping personal cancer beliefs including perceived risk and outcomes from a cancer diagnosis (Beman, 1990; d'Agincourt-Canning, 2005). In

our study, patients recalled family and friends suffering recurrence, metastasis and death after undergoing BCT; witnessing such negative sequelae following BCT was influential in women's choice for mastectomy.

HBM research has also demonstrated that the likelihood of engaging in a behaviour reflects the believed effectiveness of that behavior on reducing the perceived threat (Becker, 1974; Janz & Becker, 1984; Weinstein, 1993). The benefit of undergoing mastectomy(ies) was perceived as being highly effective by our patients. All patients in our study firmly believed that preserving any breast tissue in the cancerous breast would result in experiencing further disease and ultimately death. Studies using the HBM have demonstrated that the behaviour which maximally reduces the perceived threat while minimizing costs, will be undertaken (Becker, 1974; Champion & Skinner, 2008; Rosenstock, 1974) which for our patients was UM+/-CPM. While our patients described barriers to undertaking more extensive surgery these were overcome by either minimization (of the potential complications), or turning to social systems for support, two strategies which have been described within the HBM for resolving barriers (Becker, 1974; Gonzalez, Goeppinger, & Lorig, 1990). Applying our patients' decision-making to the HBM it is readily understood why women chose to undergo UM+/-CPM. Our patients overestimated the perceived threat of ESBC, they overestimated the benefits of undergoing UM+/-CPM and they minimized the costs of undergoing mastectomy in order to prevent the threat of death.

#### 6.4.3 Implications for Clinical Practice and Future Directions

As the increasing rates of CPM have raised concerns about overtreatment, understanding the decision-making process for ESBC is important. This study provides an understanding as to why women are choosing to undergo UM+/-CPM and how we might improve upon the decision-making process.

Our research has demonstrated that a disconnect exists between patients and their surgeons; despite surgeons recommending BCT, patients chose to undergo UM+/-CPM. This discordance reflects the patient's stronger weighting of information from personal narratives and treatment-related beliefs than the surgeon's evidence-based discussion of risks and benefits. It has been well documented that anecdotal information can transcend evidence based medicine in-terms of patient decision-making

(Borgida & Nisbett, 1977; Redelmeier et al., 1993). Personal cancer stories (narratives) dominated our patients' decision-making process, yet patients did not readily share what was most concerning for them and surgeons were often reluctant to ask; findings which are in-keeping with current literature (Beach, Easter, Good, & Pigeron, 2005; Hack, Degner, Parker, & Team, 2005; Maguire, Faulkner, Booth, Elliott, & Hillier, 1996) .

It has been demonstrated that patients who felt that their disease experience had been explored by their physician reported improved trust in the patient-physician relationship; thereby decreasing patients' anxiety and modifying their decision-making behaviour (Fiscella et al., 2004; Henman, Butow, Bornw, Boyle, & Tattersall, 2002). Physician communication styles which promote the discussion of patients' fears and concerns include: open directive questions, clarifying non-verbal cues, summarizing patients' statements, and empathy (Enkin & Jadad, 1998; Fagerlin, Wang, & Ubel, 2005; Maguire et al., 1996; Perez et al., 2014). Addressing physician communication styles may expand the discussion to include those concerns which are shaping patients' choice for more extensive surgery. Understanding the influence of narratives on decision-making can allow us to incorporate this source of information into the surgical consultation. Video narratives and pictograms used in conjunction with objective information, have a greater impact on patient knowledge and decision-making than objective information alone (Enkin & Jadad, 1998; Fagerlin et al., 2005; Mazor et al., 2007; Perez et al., 2014). The inclusion of narratives presenting previous patients' experiences with BCT, UM and CPM may complement the surgical consultation process, and modify patients' misperceptions around the risks and benefits of UM+/-CPM.

The HBM has demonstrated that patients' beliefs impact the treatment decision, therefore changing beliefs may prompt behaviour change. HBM research has successfully developed tools to modify treatment behaviours, including increasing mammography screening and BSE (Champion, 1994b; Umeh & Rogan-Gibson, 2001). Champion demonstrated that mammography screening increased more than twice, in women who received individual counseling based on their HBM perceptions (Champion, 1984; Champion, 1994b). The HBM has also been used to describe a reduction in a negative health-behaviour as seen with smoking cessation (Gibbons, McGovern, & Lando, 1991; Kirscht, 1974b; Weinberger, Greene, Mamlin, & Jerin, 1981). What is common to both breast cancer screening and smoking cessation is that behaviour change occurred through modification of

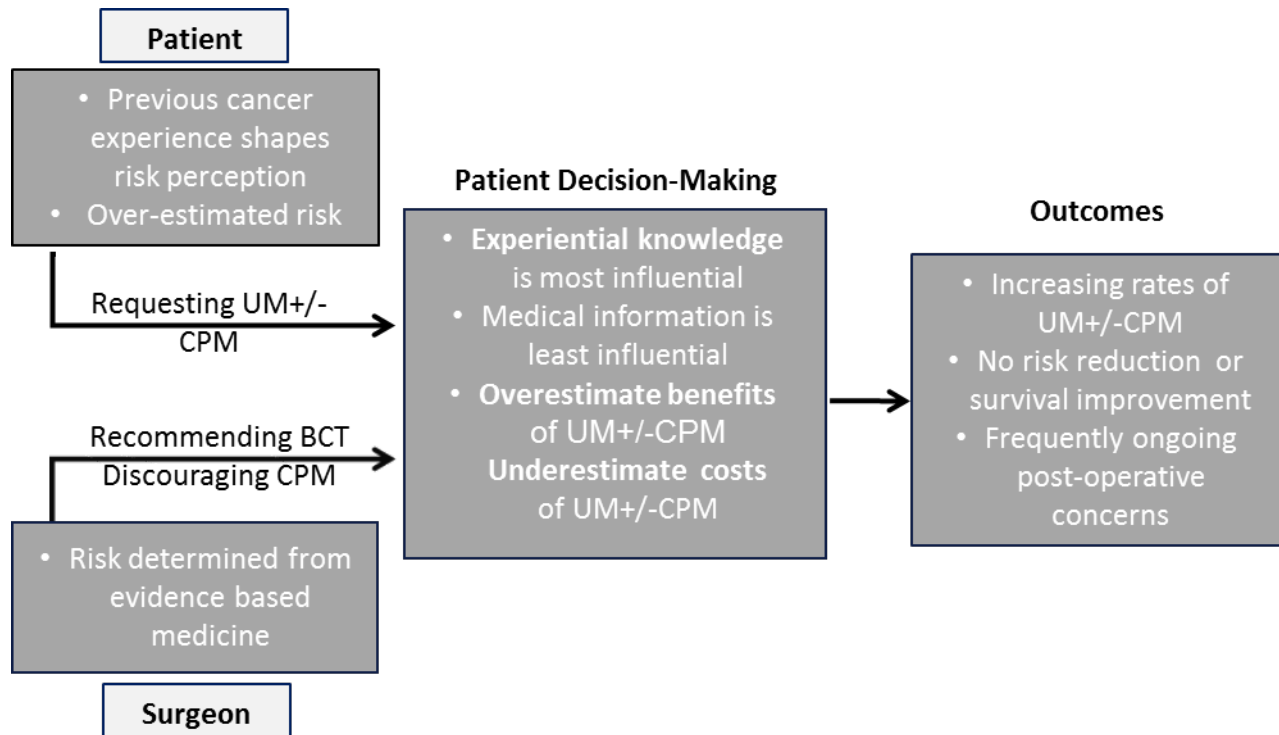
the perceived threat, in addition to the perceived benefit of undertaking that behaviour (Champion, 1994a; Gibbons et al., 1991; Kirscht, 1974b; Umeh & Rogan-Gibson, 2001; Weinberger et al., 1981). To-date there are no HBM tools developed to guide surgical decision-making, however the HBM has been theoretically described as an approach to increase bariatric surgery in the obese patient population (Armstrong, Anderson, Tran, & Nguyen, 2009). A future direction of this research would be to develop a tool which might allow health-care providers surgeons to identify those women who are choosing mastectomy(ies) based on the misperceived threat of ESBC. These women could then be provided with counseling in addition to standardized information (Champion, 1994b); ensuring that a woman's decision to undergo more extensive surgery is truly informed about both the risks and benefits and not shaped by misperceptions.

## 6.5 Conclusion

We have demonstrated that the misperceived threat of ESBC is the driving factor behind women's choice for UM+/-CPM. Experiential information was extremely influential in shaping women's perceptions about ESBC including: an overestimated risk of recurrence, contralateral breast cancer (CBC), metastasis and subsequent death. Despite surgeons recommending BCT, discouraging CPM and describing the survivability of ESBC, patients greatly over-estimated the threat of ESBC, and strived to eliminate this threat by choosing UM+/-CPM. Most women did not perceive any risks of undergoing mastectomy(ies) during their decision-making, yet many experienced long-term issues with pain, disturbed skin sensation, and body image. The findings are significant as previous literature has shown that more extensive surgery does not improve survival and has greater potential for physical long-term morbidities. Improved discussion of patient sources of information and fears around survival would benefit surgical consultations.



**Figure 10: Pictorial Representation of the Surgical Decision-Making Experience for ESBC**



## Chapter 7: Discussion

In keeping with the tenets of grounded theory, this study was guided by constant comparative analysis, the evolving concepts and categories that emerged from the data collection and the on-going analysis process. Within grounded theory the understanding of the phenomenon and the evolving theory describing that phenomenon is grounded from the data itself, a fundament that was held true for the research presented here. While grounded theory research has been used to develop new theories it can also expand upon already established theories, enriching them both in concept as well as application. The exploration of women's choice for mastectomy has resulted in the development of the central theme *'the overwhelming threat' of breast cancer: a misperceived risk* and a more enriched understanding of the Health-Belief Model (HBM) as it applies to women's choice for UM+/-CPM. Naming this central theme stemmed from the meaning patients gave to their breast cancer diagnosis, which had been derived from their knowledge and experiences, the experiences described by the surgeons, and the subsequent decisions that ensued to manage this threat. Drawing upon both cognitive and medical literature, I will demonstrate how these research findings expand upon the current formulation of the Health-Belief Model.

Section 7.1 presents an overview of the principle findings from this research. Section 7.2 outlines the HBM including its origins, tenets and suitability as a cognitive model for these research findings. Section 7.2 also presents a brief discussion around other models and their lack of suitability as a framework for these research findings. Sections 7.3-7.5 will then describe the patient, surgeon and environmental factors that influenced the choice for mastectomy. Section 7.6 will illustrate how these research findings expand upon the HBM, demonstrating its application to understanding the phenomenon of increasing mastectomy rates. Section 7.7 will then discuss the implications of these findings and future directions for research.

### 7.1 Principle Findings

This study used grounded theory methodology to explore and describe those factors that are influencing the increasing rates of unilateral and contralateral prophylactic mastectomy for the treatment of unilateral ESBC in non-high-risk women. As described in Chapters 3-6, to elucidate those factors which were influential in women receiving UM+/-CPM, interviews were conducted with both patients and treating surgeons. This research has illustrated the complexity of the surgical

decision-making process for ESBC, one which is influenced by the surgeon, the patient and the medical and sociocultural milieu.

Chapter 4 describes the meaning that women attributed to their diagnosis of ESBC. The patients in this study described receiving their diagnosis of breast cancer with fear; this fear remained present and was influential throughout the decision-making process. Despite women having multiple sources of information available, the most influential was a previous cancer experience with friends or family. The fear attached to the meaning of the breast cancer diagnosis translated into women believing that they were at high risk of recurrence from their cancer, of developing a contralateral breast cancer and distant metastasis, and ultimately of dying from their disease. Women believed by choosing more extensive surgery they could control their cancer outcomes. The decision to undergo mastectomy was a response to fear and anxiety and the belief that more surgery equated to more control of their cancer and better survival.

Chapter 5 demonstrated the role that both the surgeon as well as the medical environment play in women's cancer experiences and their decision-making processes. While MRI and reconstruction might be considered medical tools solely for the purpose of diagnosis and treatment of ESBC, they are not neutral techniques and they can influence the decision-making process. This research has demonstrated that accessing both MRI and reconstruction may serve as additional information which shaped the meaning women attribute to their threat of breast cancer and in-turn their management of this threat. Similarly, the 'neutral' surgical discussion, one where the surgeon presented all treatment options without putting forth a treatment recommendation, inadvertently shaped women's decision-making processes.

Triangulating data sources (patient and surgeon interviews) provided a deeper understanding of the decision-making process that resulted in women undergoing mastectomy, one which was reflective of the key tenets of the already established within the Health-Belief Model. Chapter 6 is a reflection of the study findings as they apply to the HBM, a theory which had been developed with the intent of describing decision-making behaviour. Comparing and contrasting the patients' disease and treatment-related beliefs with those of the surgeons' via the HBM, further elucidated the meaning that patients attributed to their diagnosis of ESBC. Patients greatly overestimated the threat of ESBC. Patients believed there was a direct relationship between leaving breast tissue in the

cancerous breast and the development of more extensive disease, resulting in death. The over-estimation of the patients' *perceived threat* became apparent when contrasted with the information provided by the surgeons. Surgeons described the risks of recurrence and CBC as low, and that more surgical treatment does not impact the likelihood of metastasis or survival. Surgeons also described the high survivability of ESBC.

Chapter 6 also describes the barriers and benefits perceived by women choosing UM+/-CPM. Patients perceived only benefits (without costs) to choosing mastectomy, believing UM+/-CPM eliminated all likelihood of recurrence, CBC, metastasis and subsequent death. Although the potential costs of undergoing mastectomy were not attended to by patients during their decision-making, many patients suffered the complications of undergoing mastectomy(ies). In contrast surgeons described no substantial benefit offered by mastectomy (over BCT) and always discussed the potential complications of the surgical options.

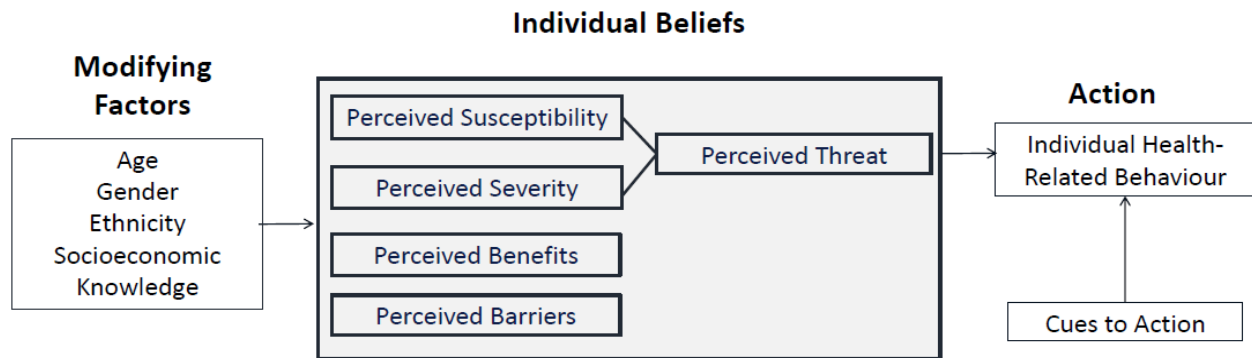
This research has demonstrated that while myriad of information impacts women's beliefs, the most influential in shaping the meaning women gave to their breast cancer diagnosis was personal narratives shared by friends, family and the breast cancer community. It is the meaning that women have attributed to their diagnosis which shaped patients' disease and treatment perceptions, resulting in women choosing mastectomy as treatment for their ESBC.

## 7.2 The Health-Belief Model (HBM)

### 7.2.1 Origins and Tenets of the Health-Belief Model

Since its inception from early public health research in the 1950s, the HBM has been one of the most widely used and accepted frameworks to examine health-related behaviours (Champion & Skinner, 2008). The HBM was originally developed in an attempts to understand why some individuals would engage in preventative behaviours (e.g. the flu shot) while others would not. The HBM was subsequently used as a framework to develop strategies that would increase preventative behaviours (Rosenstock, 1974). In the 1970s, research using the HBM further expanded its use, applying the framework to both illness behaviour (the behaviours an individual engages in once symptomatic) and 'sick-role behaviour'; i.e., the actions undertaken for the purpose of becoming well (Becker, 1974; Kirscht, 1974a). As discussed in Chapter 6, Rosenstock (1974) originally described 4

concepts (individual beliefs) of the HBM that appeared to influence treatment behaviour, including: perceived susceptibility, perceived severity, perceived benefits and perceived barriers (costs) (see FIGURE 11 below).



**Figure 11: Health-Belief Model adapted from Champion and Skinner (Champion & Skinner, 2008)**

*Perceived susceptibility* is defined as the subjective perception of the risk of recurrence of the illness, or vulnerability to the disease (Becker, 1974). *Perceived severity* is defined as the perception of the seriousness of leaving an illness untreated with dimensions including both medical consequences (e.g. death, disability, pain) as well as social consequences (e.g. effects of work, family and social relations) (Janz & Becker, 1984). Rosenstock (1974) argues that the extent of severity can be judged both on the emotional arousal created by the disease as well as the consequences of the disease. Together perceived susceptibility and perceived severity can be considered the *perceived threat* of the disease (Champion & Skinner, 2008). *Perceived benefits* are defined as those behaviours which are perceived as being potentially advantageous in reducing the perceived susceptibility and/or severity (Becker, 1974; Rosenstock, 1974). Included in this is the belief in the treatability of the disease, the belief in the efficacy of the treatment, and the value of riding oneself in the disease itself (Becker, 1974). In contrast, *perceived barriers* are defined as perceptions of the impediments and/or negative aspects related to undertaking health-related behaviours (Champion & Skinner, 2008; Rosenstock, 1974). Barriers can include any aspect of the behaviour that may be seen as inconvenient, expensive, unpleasant, or painful and can include (but is not limited to) side-effects,

duration of treatment, complexities of the treatment and the impact that the treatment has on family, work and other social relationships (Becker, 1974; Rosenstock, 1974). The HBM argues that a behaviour will only be undertaken if an individual perceives a threat (susceptibility and severity) from the illness, and that the behaviours available will lessen this threat (Rosenstock, 1974).

According to the HBM, in an instance where there are multiple behaviours which might lessen the *perceived threat*, it is that behaviour which offers the greatest benefit and the least cost (or most net benefit) which will be undertaken. Determining the potential costs and benefits of treatment options requires that the decision-maker have some knowledge (a modifying factor) of both the availability and the effectiveness of these options. In addition, it is argued that some familiarity with the disease is required to form beliefs around the potential susceptibility and severity to the individual. Placing these terms within the context of the study findings, the women in this study had already received the diagnosis of ESBC, therefore their perceived susceptibility was around the meaning that the diagnosis of breast cancer held for them. Their perceived susceptibility and severity is reflected in the vulnerability women felt to suffering recurrence and other disease processes including contralateral breast cancer, metastases and death. Women perceived that there were great benefits and little (if any) barriers to undergoing mastectomy. In contrast, patients did not perceive that BCT would lessen the threat of ESBC, thereby offering no benefits.

### 7.2.2 Self-Efficacy, an Additional Tenet of the Health-Belief Model

While *self-efficacy* was not included in the original conceptualization of the HBM, after Bandura's work on *self-efficacy* (further described below) Rosenstock later expanded upon the HBM to include *self-efficacy* as an additional tenet. *Self-efficacy* is defined as the extent to which an individual feels competent to overcome the perceived barriers and successfully engages in the health-related behaviour (Champion & Skinner, 2008; Rosenstock et al., 1988). The HBM was expanded to include *self-efficacy* following the development and illustration of Bandura's Social Cognitive Theory (SCT); a cognitive theory that was put forth in hopes of explaining how individuals process information, and the biases that influence the human learning experience (Bandura, 1977). While SCT is a broad theory which can be applied to almost all human phenomenon, it has been applied to health-care research describing central concepts that are closely related to those of the HBM. The central concepts of SCT can be divided into expectancies and implications. Expectancies include beliefs

about how events are connected (similar to perceived susceptibility), what event leads to which outcome (similar to perceived severity), beliefs about how the behaviour is likely to influence the outcome (similar to perceived costs and benefits), and beliefs about one's own ability to perform the behaviour (i.e. *self-efficacy*) (Bandura, 1977; McAlister, Perry, & Parcel, 2008). Implications are defined as the value given to the outcome (for instance, remaining free of breast cancer would hold a high value), thereby increasing or decreasing the likelihood of undertaking a behaviour dependent on the perceived value (implication) of the outcome behaviours (similar to the value of the removing the *perceived threat*) (Bandura, 1977; McAlister et al., 2008). As the central ideas in the HBM are the value placed on the illness (in this instance breast cancer) and the expectancy that the behaviour (i.e. mastectomy) undertaken will modify the illness, it becomes readily apparent how *self-efficacy* as defined in SCT (i.e. how the belief in an individual's ability to undertake a behaviour) complements the original HBM. Examining the central concepts of the SCT it can be seen how adapting the HBM to include *self-efficacy* increases the understanding put forth when using the HBM.

### 7.2.3 Other Health-Behaviour Models

The central theme to this research (constructed from the patient and surgeon interviews) was the '**overwhelming threat**' of *ESBC* and the need to manage that threat. These findings are most in-keeping with the HBM as opposed to other health-behaviour models. While the tenets of the SCT are closely related the HBM, SCT has been most frequently used within health-care research to explore phenomenon where the environment might play a substantial role in either promoting or inhibiting behaviour; such as an individual with chronic diseases over-coming challenges which prevent ideal health-behaviours (for instances barriers to regular health check in diabetic patients), or an individual behaving in a manner which would be considered socially aberrant (such as unprotected sex despite being aware of the risk for HIV/AIDS) (McAlister et al., 2008). While external environment did play a role in the decision for mastectomy the influence was largely through the meaning that patients attributed to breast cancer as illustrated below in sections 7.3.2 and 7.5.5.

Leventhal's (1980) Common Sense Model (CSM), another health-behaviour model, was developed in an attempt to depict how *illness representations* (further described in section 7.3.2) determine an individual's appraisal of an illness situation and their resultant health behavior. The CSM has been

most frequently used for chronic conditions and has not been used to demonstrate why an individual would engage in one behaviour rather than another (unlike the HBM). For this reason, in attempting to ascertain what was influential in women's choice for mastectomy, the research findings presented here were most in keeping with the framework of the HBM rather than the CSM. However, the CSM lends the concept of illness representation, which is not offered through the constructs of the HBM. The role of *illness representations* in women's decision-making is further discussed in section 7.3.2

The Theory of Reasoned Action (TRA) and the very closely related Theory of Planned Behaviour (TPB) are also well known health-behaviour models. While the TRA/TPB are similar to the HBM in that they are also based on expectancy, the central tenet differs. TRA/TPB assume that the best predictor of behaviour is the behavioural intention, which is determined by both personal attitudes and social norms (Montano & Kasprzyk, 2008). As described in Chapter 6, and further demonstrated below, the choice for mastectomy(ies) was driven by women's perceptions of the threat of ESBC and the expectancy that without undergoing UM+/-CPM women would die from their disease; the implication of undergoing mastectomy being the threat of ESBC would be eliminated. The value that women placed on their diagnosis, the expectations that women held for their ESBC, and the perceived implications of choosing to undergo UM+/-CPM, are most in-keeping with the HBM. Furthermore, while inter-personal relationships played a role in shaping the construction of *perceived threat* (section 7.3.2), social norms played little if any, role in women's desire for more extensive surgery, as 70-80% of women with ESBC undergo BCS (section 7.3.4) (Gaudette et al., 2004). Other notable theories in health-behaviour include both the Transtheoretical Model (TTM) and the Precaution Adoption Process Model (PAPM). These theories examine behaviour through its stages of change, from pre-contemplation to completion. The decision-making process as experienced by the patients in this study was not reflective of stages of change and thus these theories were not consistent with the perspectives shared by our participants.

While no one health-behaviour theory is complete, through its extensive application in health-care literature, the HBM has been demonstrated to be a useful theory for understanding health-behaviour. The HBM constructs have gained substantial empirical support, demonstrating their use in both predicting behaviour as well as developing tools with the intent of changing behaviour (Janz & Becker, 1984). The concepts of the HBM are inclusive of, and often overlap with, other formal



behaviour theories (such as SCT), yet remain broad enough to include factors that may be relevant to health-behaviour which have not been routinely included in formal frameworks. For instance, an argued limitation of the HBM is its failure to include important social, inter-personal and contextual issues. However, when examining FIGURE 11 (above) social and inter-personal relationships might be considered modifying factors. The discussion presented below aims to challenge these limitations and demonstrate how the framework of the HBM allows for the inclusion of other decision-making literature. For instance, the role of the interpersonal patient-provider relationship including the decision-making dyad, appeared to indirectly shape a women's choice for UM+/-CPM. While the patient-provider dyad has gained substantial attention in health-care literature, to-date the role of the dyad has not been examined in a meaningful manner within the HBM. In addition, the discussion below demonstrates how contextual issues with the medical management for ESBC (such as MRI and reconstruction) may indirectly influence a woman's decision-making process. In the discussion below, I will demonstrate such knowledge sources were important to the women in this study, and in-part shaped the meaning that women gave a diagnosis of ESBC, and challenge that the HBM can be expanded to include the social, contextual and inter-personal issues which influenced the construction of ESBC and its *perceived threat* for women.

## 7.3 The Role of the Patient

Chapter 4 and 6 present the results of the interviews conducted with the patients who chose to undergo UM+/-CPM for the treatment of their ESBC. This study reflects the disease experience and decision-making processes as understood by our patients. It illuminates the role that the patient plays in the resultant mastectomy, describing the previous experiences, risk perceptions, and *illness representations* which were prominent in women's surgical decision-making.

### 7.3.1 Risk Perception

The patients in this study perceived the risks from a diagnosis of ESBC as substantial. Patients misjudged the risk of events associated with ESBC, including the risk of ipsilateral recurrence, the development of CBC, and the 'spread' of their cancer as distant metastasis. Women believed these events to be inevitable, and expressed with certainty, that without undergoing more extensive surgery there was an almost absolute likelihood that they would experience one or all of these

events. In addition, all patients felt that they were at substantial risk of dying from their disease. Patients also voiced the ‘unavoidability’ of the step-wise progression that would ensue should these events occur (that being, ipsilateral recurrence and/or a CBC would lead to metastasis and subsequently death).

Risk perception is defined as the subjective assessment of the likelihood of a negative event occurring, and the presumed consequences associated with that event. In contrast, formal measures of risk calculate the probability of the event and the magnitude of the potential consequence should that event occur. Cognitive psychology has demonstrated that formal measures and ‘lay’ perceptions of risk can differ substantially, with lay perceptions frequently overestimating or underestimating actual risk (Douglas, 2003). Early research on risk perception suggested that these differences were due to individuals having inadequate or incorrect information and therefore, providing additional information would result in perceived risk reflecting actual risk. However, it has since been demonstrated that additional information alone does not modify risk perceptions to be reflective of actual risk (Douglas, 2003). The reason being, that risk perception is shaped not just by numerical estimates, but also by a multitude of cognitive factors including the *representativeness* and *availability* of the event, the *emotion* (affect) associated with the event, and the *social amplification* (or attenuation) (further described in section 7. 3.2c) of the actual risk associated with the event (Kasperson et al., 1988; Slovic, Finucane, Peters, & MacGregor, 2004; Tversky & Kahneman, 1974).

### 7.3.1.1 *Representativeness and Availability Heuristics*

Tversky and Khaneman (1974) described *representativeness* and *availability* as heuristics, or a ‘set of rules’, that individuals employ to determine the likelihood of an event occurring.

*Representativeness* is defined as a strategy used to determine ‘the probability that event A originates from process B’ (Tversky & Kahneman, 1974). Applying this heuristic to breast cancer it is readily understood how events such as recurrence and metastasis are attributed to a diagnosis of ESBC.

*Availability* is defined as the assessment of the frequency of the event by the ease with which the events are brought to mind. An event that is highly salient and easily recalled or imaged will seem to be of high frequency (Tversky & Kahneman, 1974).

### 7.3.1.2 Role of Emotion (Affective Pathway) in Risk Perception

The role that emotion plays in risk perception has been well described in cognitive literature (Alhakami & Slovic, 1994; Slovic et al., 2004; Zajonc, 1980). It is believed that an individual can assess and respond to risk through two systems, analytic and affective (emotional). Affective responses occur through the use of metaphors, narratives, and images, to which feelings are attached (Finucane, Alhakami, Slovic, & Johnson, 2000; Hendrickx, Vlek, & Oppewal, 1989; Slovic et al., 2004). Analytical responses are those that use logic and reasoning to appraise situations or events (Epstein, 1994; Slovic et al., 2004). In contrast, affective responses are intuitive, occur almost automatically, and are often made with greater confidence than analytical responses (Epstein, 1994; Slovic et al., 2004; Zajonc, 1980). It has been demonstrated that strongly negative affective responses can evoke overestimated risks despite very small probabilities of the event occurring (Loewenstein, Weber, Hsee, & Welch, 2001; Rottenstreich & Hsee, 2001). Research conducted by Hendrickx et al. (1989) demonstrated when an individual is presented with both negative narratives and numerical frequencies of an event, the narratives induce greater perceptions of risk (likelihood) of that event occurring. Furthermore, Hendrickx (1989) demonstrated that when presented with both frequencies and narratives simultaneously, individuals preferentially attend to the narratives in shaping risk perception. Numerical information was only preferentially used when narrative information was not available, was not concrete enough to be relatable, and the individual had no outside knowledge (similar to Tversky's availability heuristic) (Hendrickx et al., 1989). It can be argued those events that evoke *representativeness* and *availability* heuristics (being familiar and highly salient) are also likely to evoke affective responses, making these cognitive approaches to risk perception intertwined.

Research on risk perception has demonstrated that the affective pathway is frequently more dominant in shaping risk perception than the analytical pathway. Research conducted by Hendrickx, Borgida and Redelmeir suggests why the affective pathway is preferentially used to assess risk. Similar to Hendrickx's findings, Borgida and Nesbitt (1977) demonstrated that individuals preferentially used anecdotal, rather than numerical, information even when the numerical information was pertinent. Borgida (1977) found that anecdotal information was preferentially attended to as it was vivid (easily recalled and imagined), and evokes an emotionality (in keeping with both availability and affective risk perception). In contrast, numerical information is abstract

and not personified, generating less meaning for the participants. Borgida (1977) also demonstrated the value of numerical information is often not understood outside of individuals who have a limited background in numerical literacy (statistics), for instance, the meaning of a positive finding from a robust sample size might be lost. In contrast, even small repetitions of anecdotal information strengthened the perceived risk. Hendrickx (1989) has also demonstrated that the preference for narratives in shaping risk is due to the affective response, and the affective response will outweigh analytic responses particularly when the affective emotions are strongly negative. Redelmeier (1993) described that the intensity of the negative emotions (ex. worry) associated with the event, results in an increase in perceived risk with more intense emotions. In addition, numerical discussions of risk reduction do little to ease these emotions. For instance describing a risk reduction from 15 in 10,000 to 10 in 10,000 (an already small risk) had little effect on decreasing anxiety, whereas a drop to 0 removed worry entirely and resulted in minimal perceived risk (Redelmeier et al., 1993). When examining this risk numerically the risk estimate decreased from 0.15% to 0% which overall is minimal absolute change, but elicits a very large emotional response.

Taken together, this research provides insight into why women's risk perceptions were preferentially shaped by experiential knowledge rather than information provided by their surgeons and the health-care teams (further discussed in sections 7.3.2). As described in Chapter 6 and section 7.4.3, the surgeons in this study spoke in terms of numerical risk, using evidence-based medicine to calculate risk estimates via the analytical pathway. Surgeons stated the risks of recurrence and CBC were low in non-high-risk ESBC and the likelihood of survivability was high, often providing statistical estimates of the likelihood of these occurrences. However, much like the findings from Hendrickx's (1989) study, patients in this study did not attend to these numerical estimates, rather the meaning of a breast cancer diagnosis and the associated risk was shaped by narratives which elicited feelings of fear and anxiety. These findings are not unique to the women in this study. It has been well documented that anecdotal information can transcend numerically based information in-terms of patients' risk perceptions and decision-making (Borgida & Nisbett, 1977; Redelmeier et al., 1993).

### 7.3.2. Illness Representations

#### 7.3.2.1 Illness Representations derived from the Common Sense Model

While availability heuristics and the affective pathway may be responsible for shaping patients' risk perceptions, it is also necessary to appreciate the meaning (or *illness representations*) women attributed to a diagnosis of breast cancer. Leventhal (as part of the Common Sense Model) described *illness representations* as the beliefs and expectations a patient has about an illness (Leventhal et al., 1980). Leventhal posits that illness representations are constructed through 3 sources of information: '*lay information*', *authoritative information* and the *illness experience* to-date. *Lay information* is defined as information which is derived from social communications and cultural representations of the illness. *Authoritative information* is that which is provided from the medical community or any other source seen to be authoritative. The *illness experience* is information which is based on current symptoms or previous experiences, including previous treatments used for the illness (Diefenbach & Leventhal, 1996). The CSM lends the concept of illness representation, which is not offered through the constructs of the HBM. However as the illness representation is the meaning women attributed to their breast cancer diagnosis, it is necessary to consider both how that illness representation was shaped, and the role which illness representation played in patients' risk perceptions. For this reason, both *illness representations* (derived from the CSM) and the tenets of HBM will be applied to the research findings around the decision-making processes for ESBC.

#### 7.3.2.2 Illness Representations: Surgical Decision-Making for ESBC

As described by the CSM, the sources of information for patients in this study were threefold including '*lay*' *information*, *authoritative information*, and the *illness experience*. The meaning attributed to the diagnosis of breast cancer was most profoundly shaped by the *illness experience*, which for the women in this study, included *personal events* and *witnessed experiences* of friends, and family members. *Personal events* included those that occurred prior to receiving their diagnosis, the inciting episode (a discovered lump or a routine mammogram), and the occurrences that followed. Irrespective of whether the women had been actively screening or inadvertently found their cancer, the diagnosis of cancer elicited the emotions of shock and fear in all patients. Some women also described complexities during the work-up of their diagnosis, requiring further imaging (often MRI) and additional biopsies. For these women, fear of their diagnosis was heightened

throughout the process of undergoing multiple imaging tests and biopsies. The positive association between the use of MRI and the increasing rates of mastectomy have been well described in the literature and are further discussed below in section 7.5.1. However, the role that additional investigations (such as MRI) played in shaping the meaning women attribute to breast cancer is reflected through the emotions expressed by the patients. Those patients who required further imaging became fearful about the extent of their disease, including its potential to remain in the breast undetected, and then present ‘*over and over again*’. Those patients whose disease had only been detected on MRI became uncertain about the potential for mammogram to detect future disease, and fearful of the potential for further disease to ‘return’ unmonitored. A similar experience was shared by the patients in this study who experienced a prolonged time to diagnosis and required multiple biopsies as part of their work-up. Not only did the additional work-up heighten women’s fear, it also led them to believe that any disease recurrence or progression would not be readily detected as cancer. This belief added to their perceived benefits of undergoing UM+CPM. Further, future surveillance was believed to be both ineffective and potentially harmful should future disease go undetected. Increased distress after undergoing additional cancer work-up has been well described in the literature (Heckman et al., 2004; Lampic, Thurfjell, Bergh, & Sjoden, 2001; Montgomery & McCrone, 2010; Schou Bredal, Karesen, Skaane, Engelstad, & Ekeberg, 2013). In-keeping with the experiences of the women in this study, a study conducted by Lampic et al. (2001) demonstrated that the more diagnostic tests patients had to undergo the more elevated their anxiety became during the diagnostic work-up. In addition, it has also been demonstrated that an increased time interval to definitive diagnosis was associated with a higher level of anxiety when compared with women who experienced a shorter delay (Ferrante, Chen, & Kim, 2008; Lebel et al., 2003). Importantly, Schaepe’s (2011) study exploring the cancer diagnosis experience demonstrated that difficulties and delays in diagnosis led patients to believe that they would face similar difficulties in the future, much in-keeping with the fears expressed by our patients. In our study, the fear evoked by the complexity of the work-up and time to diagnosis shaped patients’ misperceptions around the likelihood of recurrence and ‘spread’ from their ESBC.

Many of the patients in this study described how they had previously lived through a cancer experience (*witnessed experiences*) with family or friends. These experiences were predominately negative, as many women described witnessing friends or family ‘*suffering*’ from breast cancer

recurrence, metastasis and/or death. This experiential information was highly valued by our patients as they expressed having first-hand knowledge of *'what breast cancer looks like.'* Those experiences which were most influential and left the most-lasting impressions were loved ones who had been *'lost to cancer'*. Stories of family and friends with breast cancer heightened our patients' own fears, shaping their beliefs about what a diagnosis of ESBC might mean for them. This personal fear, derived from experiential knowledge, remained present with our patients throughout their entire decision-making process and was influential in the choice for UM+/-CPM. Del Castillo et al. (2011) explored the illness beliefs of individuals who had, and had not, lived with someone who had cancer. Del Castillo (2011) described that thoughts of cancer evoked strongly negative feelings across both populations. Even within a healthy population that had had no previous experience of cancer, holding a fear of cancer resulted in an overestimation of mortality due to cancer (Del Castillo et al., 2011). Similar to our research findings, those individuals who lived with a family member affected by cancer experienced substantially stronger negative feelings of worry and fear when faced with the possibility of a cancer diagnosis themselves.

In our study the role of experiential knowledge was not limited just to those patients who had either an affected family member/friend or difficulties with their own diagnosis. Patients without a previous personal experience recalled becoming very quickly connected with other women in the breast cancer community and networking with other breast cancer patients. Hence they accessed a source of *'lay' information* as described by Leventhal. Breast cancer is a common disease and is estimated to affect 1 in 9 women (Public Health Agency of Canada, 2012) and as described by a patient in this study *'everyone knows someone who had breast cancer.'* Turning to friends and family as sources of information, along with networking with other breast cancer patients, has been described in the literature examining decision-making for breast cancer (Benedict et al., 2001; Stafford et al., 1998).

Approximately one-quarter of the patients in these studies connected with, and were substantially influenced in their treatment decision-making, by women who previously had breast cancer (Benedict et al., 2001; Stafford et al., 1998). Much like the experiential knowledge our patients shared about the suffering and loss of family and friends, the information received through

networking with other patients was frequently negative. Women shared stories of recurrences, development of CBCs, metastases and importantly regret around their choice for BCT.

In contrast to the illness experience and the lay sources of information, ***authoritative information*** was that which was the least meaningful to our patient's *illness representations*. While all patients described how the health care team served as a useful source of information, that information did little to shape the meaning that breast cancer held for them. In contrast to the embodied experience of breast cancer which was shared through personal narratives, the information provided by the surgeons was presented as objective and de-personified. Patients describe having been informed that the surgical options for ESBC included BCT and UM, and that these were considered equivalent treatment options with one surgery offering no survival advantage over the other. Women were informed that the risk of ipsilateral recurrence was small, even with BCT, and mortality from ESBC was low. Patients were also aware that undergoing breast conserving surgery would require radiation therapy (RT). While many women were unaware that there was a potential for RT even in the setting of mastectomy, all patients were informed that their surgical choice would not impact the need for hormonal and chemotherapy. Surgeons did not routinely describe CPM, nor did they recommend this procedure. Patients were informed that having a CPM would not improve long-term survival. Overall those women who chose UM+CPM felt very discouraged from this decision by their surgeons. Patients also stated that their surgeons had informed them of the advantages and disadvantages of both BCT and UM. Interestingly, while patients recalled the potential disadvantages being described, they did not recall what these disadvantages actually were. The potential disadvantages, particularly for UM+/-CPM did not appear to have been meaningful to the women in this study and therefore were not incorporated into patients' *illness representations*. The impact of this is further described in section 7.6.

### ***7.3.2.3 Role of Illness Representations on Risk Perceptions***

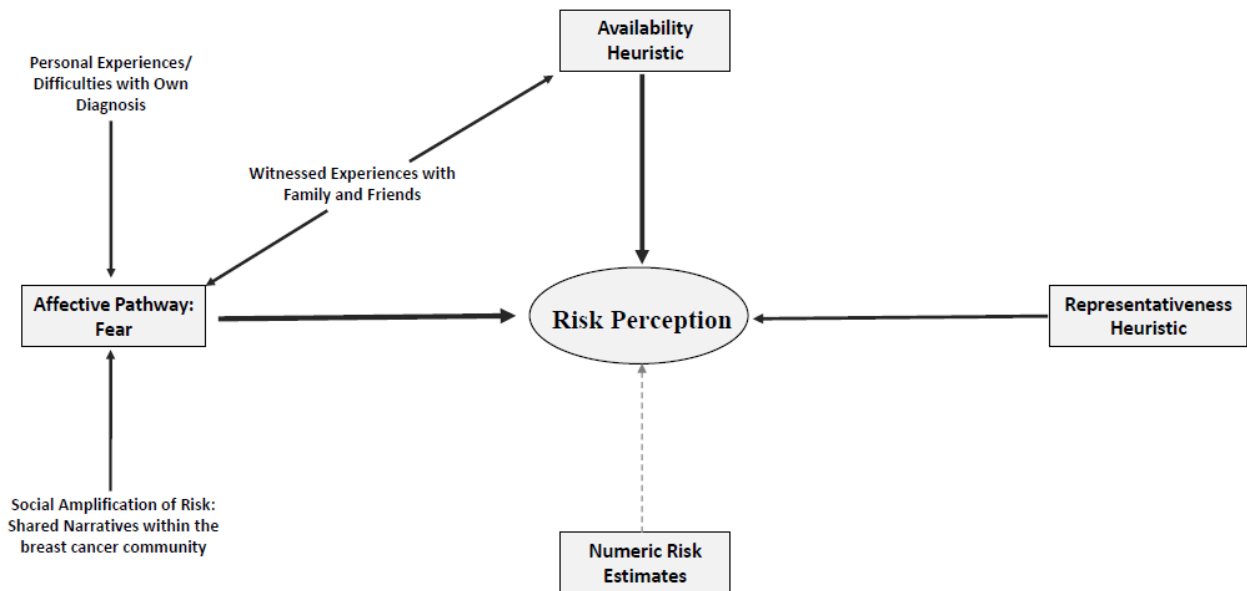
To gain an understanding of the decision-making process resulting in women's choice for mastectomy, it is necessary to appreciate *illness representations* and their influence on risk perceptions (FIGURE 12 below). Patients' experiential memories were highly salient and easily recalled (in keeping with Tverskey's *availability heuristic*). Research has demonstrated that negative affective memories and responses to a situation shape the perceived risk of that situation as high, this



was true even when the actual risk was presented as low (Alhakami & Slovic, 1994; Slovic et al., 2004). Conversely, when individuals had positive affective memories and responses, the situation was perceived as low risk (Alhakami & Slovic, 1994). The *illness representations* of women in this study were predominately shaped from negative personal experiences which elicited fear. In-turn, this fear shaped women's perceptions of ESBC as a high risk disease. In addition, research has demonstrated that risk perception can be shaped even in the absence of personal experience. Kaspersen's (1988) *social amplification* of risk theory describes how perspectives about risk can be learned about through the experiences of other's. Kaspersen (1988) suggests that information shared through personal narratives (including un-witnessed events) can impact risk perception through the extent of the information (*availability*), the *emotions* the information elicits, and the meaning this information provides to the receiver (not unlike the '*shared identity*' further described below ) (Kaspersen et al., 1988). In their research on breast cancer *illness representations* held by healthy women, Anagnostopoulos & Spanea (2005) described how unaffected women who believed they were vulnerable to breast cancer identified with women with a known diagnosis of breast cancer. This shared identity shaped their *illness representations*. Similarly, based on their research about risk, Elster and Lowenstein (1992) argue that events experienced by another individual can shape one's own preferences. Similarity in events allows an individual to determine a preference through the previous experiences (and the attached emotions) of another individual.

Despite our patients in this study being from a non-high risk population, the findings are in-keeping with what has been demonstrated in the literature among high-risk breast cancer families. In her research on consent for genetic testing, Bernhardt al. (1997) described patients over-estimating their personal risk of breast cancer if they had witnessed cancer in family or friends. Research on communication within breast cancer families demonstrated that the emotions associated with sharing cancer knowledge impacted the perceptions of unaffected family members' risk (Kenen et al., 2004). D'Agincourt-Canning's (2005) study provides insight into the mechanism by which the experiences of others influences risk perception. A diagnosis of BRCA generated a '*shared identity*' between those newly diagnosed and previously affected loved ones. This shared identity resulted in the knowledge that was gained through the experiences of others being applied personally, shaping both risk perceptions and a sense of what a future with breast cancer might hold.

In-keeping with the aforementioned literature, it was found that the meaning women in our study attributed to the diagnosis of breast cancer and their overestimated risk was shaped by the salient, emotional narratives they recounted. Patients developed a ‘shared identity’, as their new breast cancer diagnosis resonated deeply with previously witnessed (or described) cancer experiences. In-turn, patients felt equally vulnerable from their diagnosis of breast cancer. This shared identity shaped their understanding of breast cancer and its sequelae, resulting in women’s risk perception being reflective of their experiential knowledge rather than objective risk assessment. Despite women being informed by their surgeons about the low risks of recurrence, metastasis and death associated with ESBC, women continued to greatly over-estimate those risks for themselves. In addition, the choice for mastectomy (which evoked a feeling of control) was perceived to be of high benefit and low risk. While control is not a positive affect it has been demonstrated to be inversely associated with feelings of fear and dread (Sandman, 1989).



**Figure 12: Conceptual Representation of Risk Perception as shaped by the Affective Pathway (influenced by Illness Representations), Tversky’s Heuristics and Numeric Risk Estimates**

### 7.3.3: Self-Efficacy

As described in section 7.2, within the context of the HBM, *self-efficacy* is defined as the extent in which an individual feels competent to engage in the health-related behaviour and overcome the *perceived threat*. Within the CSM, *illness representations* are not constructed nor conceived within the context of *self-efficacy* however, I would argue that *self-efficacy*, as applied to health-behaviour, is constructed in-part, with the meaning that an individual attributes to the illness. Bandura (1977) suggests that *self-efficacy* is shaped ‘by past experience and by one’s attribution of success to chance or skill.’ Bandura (1977) also argues that perceived control (individual’s perceptions about their personal control to obtain a desired outcome), can only be understood in terms of *self-efficacy*; i.e. an individual must also feel capable of engaging in the behaviour that they feel will achieve control. Bandura (1977) states that there are 4 concepts which shape *self-efficacy*: *performance accomplishments*, *vicarious expectations*, *emotional states* and *verbal persuasion*. *Performance accomplishments* are previous personal experiences which increase *self-efficacy* through repeated successes (Bandura, 1977). For instance, if an individual consistently engaged in physical activity and always maintained good health, an individual may feel that engaging in physical activity may improve their health when unwell. It is also theorized that if an individual experienced a previous failure which were later overcome by determined effort, then it will be expected that even the most difficult obstacles might be overcome through sustained effort (Bandura, 1977). Through such obstacles individuals develop generalizable skills which can be applied across a number of stressful/fearful situations (Bandura, 1977). While previous life events were not directly explored in this study, many women described being accomplished in their lives, including their fields of employment, study and/or within their families. Some women even described overcoming adversity at previous moments in their life, most notably dealing with the suffering or loss of a loved one to cancer. Previous quantitative literature has demonstrated that more often women with higher levels of education and higher socio-economic status that are choosing CPM (Nekhlyudov et al., 2005; Tracy, Rosenberg, Dominici, & Partridge, 2013). This relationship appears to be paradoxical as it is believed that women with higher education should display higher rates of health literacy and therefore be less likely to overestimate their risk and less inclined to choose CPM. However, women who have overcome adversity in the past may have higher rates of *self-efficacy*, therefore the barriers

encountered during their decision-making (including resistance from their surgeons, as further described below), will be more readily negated.

*Vicarious expectations* are much like shared identities which shape *illness representations*; through observation of the differential effects of actions (for instance choosing BCT and experiencing recurrence), individuals are then able to form beliefs around which response might be efficacious. Bandura (1977) also suggests that in shaping *self-efficacy*, vicarious expectations can be intertwined with *emotional states*. An aversive occurrence, even if vicariously experienced (as was the case with our participants having witnessed friends and family with breast cancer), creates a negative expectation that can activate feelings such as fear. A large emotional arousal may result in avoidance behaviour however, it may also generate a defensive behaviour with the intent of reducing the negative emotion (Averill, 1973). The final concept believed to shape *self-efficacy* is *verbal persuasion*, where through discussion, an individual is led to believe that they can overcome an obstacle that might seem overwhelming (Bandura, 1977). It is possible to see how any of these concepts may have shaped our patient's beliefs around their *self-efficacy*, and in-turn their ability to overcome barriers associated with the choice for mastectomy. However, *self-efficacy* is a construct which is developed over time through a number of influences, and once established may be generalizable to other obstacles. This research study did not explore those previous experiences throughout women's lives which may have been most influential in shaping women's concepts of their own *self-efficacy*. In particular, the role of performance accomplishments in shaping *self-efficacy* in women's choice for CPM may further lend to the understanding of this phenomenon and therefore is potential area for further research.

### 7.3.3.1 Self-Efficacy: Taking Control of Cancer

While this study did not explore how *self-efficacy* was constructed for women choosing mastectomy, it did elucidate the role that *self-efficacy* played in women's decision-making. In Chapter 4 it was described that 'Taking Control of Cancer' was the dominant theme that emerged from women's discussion of their decision-making for ESBC. While women described interacting with their surgeons, sharing their decision-making with family and friends and seeking out additional sources of information (be it through support groups, networking with cancer patients, or turning to blogs on the internet), women considered the decision to be solely theirs. Furthermore, many women

(particularly those who chose UM+CPM), described being discouraged by their surgeon, and occasionally friends and/or family who felt that undergoing mastectomy(ies) was '*too much surgery*.' As described in Chapter 6 the only barrier that women perceived in their decision to undergo UM+CPM was the opposition they experienced by their surgeons. However, women readily minimized this opposition stating that this was their choice alone. Only one patient in the study described undergoing UM rather than UM+CPM after feeling strongly discouraged by her surgeon. This patient felt that she did not possess the capability to make the decision for more extensive surgery when faced with disagreement; however the remaining participants in this study did not voice such uncertainty, demonstrating the role of *self-efficacy* in their decision-making. Some patients also described selectively sharing their decision only with family or friends who they thought would be supportive and with-holding their surgical decision (or the diagnosis of breast cancer in its entirety) from individuals whom they thought would disapprove, further demonstrating the autonomy in women's decision for UM+/-CPM.

As described above, a negative emotional arousal may elicit a defensive behaviour. In this study patients' response to the fear experienced following a diagnosis of ESBC was to opt for UM +/- CPM as a means of negating this fear. In early literature on personal control of aversive stimuli, Averill (1973) states that 'control' is achieved through appraisal of the situation as well as removal of the stimuli. Averill (1973) argues that when a situation is seen as complex, a person not only obtains information about the situation (upon which they can act), but they also ascribe meaning to the situation (not unlike Leventhal's *illness representations*); control is then achieved by addressing the meaning (and potential consequences) given to a situation. Applying Averill's definition to the findings presented in this study, the meaning that women attributed to a diagnosis of breast cancer was shaped by their experiential knowledge which evoked an overwhelming sense of fear. For our patients the diagnosis of ESBC was perceived as a threat which would result in recurrent disease and subsequent death. The decision to undergo UM+/-CPM served to both remove the negative stimuli (the current cancer) as well as managing the *perceived threat* by removing (as defined by the meaning attributed to a diagnosis of ESBC) any potential future disease and death. Women believed they could control both their fear of cancer and their cancer outcomes by choosing to have more extensive surgery; ensuring that they would '*never have to go through this again*'. More surgery was thought to definitively prevent ipsilateral recurrence and the development of a CBC, translating into

the belief of improved long-term survival. For the patients in this study more surgery was seen as exerting control over their cancer.

As described in chapter 4, the perceived ability to control illness as well as regulate emotional response to a threat, was originally defined by Pearlin and Schooler (1978) as the coping strategy, '*mastery*', the extent to which an individual perceives their outcomes as being under their control. The use of mastery in the setting of health-care decision making has also been described in prostate cancer; a disease similar to breast cancer where multiple surgical options are available (Maliski, Heilemann, & McCorkle, 2002). While there has been substantial literature describing the role for *self-efficacy* and mastery in improving cancer patients' psychological outcomes (including quality of life, anxiety/depression, psychosocial adjustment and general distress), a recent literature demonstrated that there has been little evidence correlating control beliefs and improved health outcomes (Neipp, Lopes-Reig, & Pastor, 2007). The reason for this might be due to biases in measuring control, with the assumption that 'taking control' should result in better health outcomes for all patients. A study of breast cancer patients who used different coping styles (both acceptance and active control) demonstrated that it was women who incorporated both acceptance and active control into their coping styles which demonstrated the best psychological adjustment, both immediately after their diagnosis, and in an 8 month follow-up (Astin et al., 1999). In contrast, women who desired a high level of control and demonstrated only active control as a coping style, had worse psychological adjustment in follow-up including higher rates of depression and anxiety (Astin et al., 1999). These findings may in-part be related to control mismatches such as seen with to the concept of '*exaggerated control beliefs*', where an individual tries to control a situation when the outcome is unchangeable (Henselmans et al., 2010; Shapiro Jr., Schwartz, & Astin, 1996; Taylor, 1999). Despite surgeons counselling otherwise, the patients in this study believed that they had improved their survival by choosing to undergo mastectomy, this belief is an 'exaggerated control belief' as it has been established that more extensive surgery does not impact survival. However, as described in Chapter 4, patients using mastery and exaggerated control as a coping strategy might be at high risk of psychosocial morbidity if disease recurs. Tomich and Helgeson (2006) studied the impact of personal control beliefs in women who *did* and *did not* have a recurrence of breast cancer. Women reported using personal control as a coping strategy demonstrated worse mental and physical health in the face of recurrence, in comparison to those women who did not hold high

personal control beliefs, suggesting that personal control is only a feasible strategy in situations where the outcome may be controllable (Burger, 1989; Tomich & Helgeson, 2006). In addition, even in those women who did not recur, women who used personal control as a coping strategy reported slightly worse mental and physical health than those women who did not have high control beliefs (Tomich & Helgeson, 2006). All of the patients in this study chose mastectomy(ies) as they wanted to **ensure** this would ‘*never happen to them again*’ demonstrating exaggerated control beliefs, in the setting of disease progression (an outcome not controllable through more extensive surgery).

### 7.3.4 Summary: Risk Perception, Illness Representations and Self-efficacy in Decision-Making: Application to the Health-Belief Model

This research has demonstrated that those patients who chose to undergo UM+/-CPM did so in response to the meaning they attributed to a diagnosis of ESBC, a meaning which was preferentially shaped by cancer narratives and resulted in a diagnosis responded to with anxiety and fear. Personal experiences and cancer narratives translated into patients believing that they were at very high of ipsilateral recurrence, CBC, metastasis and inevitably, subsequent mortality.

Patients shared their concerns around ‘*the cancer returning*’, the cancer ‘*spreading*’ and the need to ensure they would ‘*survive their breast cancer*’. These fears prevailed despite discussions with the surgeons describing the low risk of recurrence and CBC, and the high survivability of ESBC. Participants voiced their beliefs that if all the breast tissue was removed then the ‘cancer couldn’t come back,’ and they would in-turn survive breast cancer, demonstrating the role in overestimated risks and misperceived benefits in the choice for UM+/-CPM.

Examining the central tenets of the HBM patients perceived that they were highly susceptible to, and overestimated, the potential negative sequelae of breast cancer. Patients voiced these beliefs with substantial fear and apprehension signifying the meaning that ESBC had been given. Patients’ perceptions of *susceptibility* to recurrence and ‘spread’ were constructed from multiple sources of information but most predominately, from those experiences of family members or friends with breast cancer, in addition (for some of the women) the personal experience during the diagnosis of their own cancer. Patients also overestimated the *severity* associated with the diagnosis of average-

risk ESBC. All patients felt that they were at substantial risk of dying from their disease. Much like their perceived susceptibility, patients' perceived mortality was voiced with fear.

Within the framework of the HBM, perceived susceptibility and severity are risk perceptions which are specific to the effect of a disease; with susceptibility being the risks of sequelae of the disease, and severity the risk of the outcomes if the disease is left untreated. As described in sections 7.3.1 and 7.3.2 risk perceptions are substantially influenced by narratives, which not only create a shared identity through perceived similarities and likenesses, but also elicit an affective response. Affective risk perceptions are both preferentially used, and associated with the overestimation of the magnitude of the risk, even when information for analytic risk assessment is available (Borgida & Nisbett, 1977; Slovic et al., 2004). Personal narratives are vivid, and therefore easily recalled and evoke an emotional response, and repetitions of the same (or similar narratives) strengthen the perceptions associated with the narratives (Borgida & Nisbett, 1977; Hendrickx et al., 1989). It is readily appreciated how stories of recurrence, metastasis, death and regret shared by family, friends, or women from the breast cancer community shaped women's personal *illness representations*, i.e. what a diagnosis of ESBC might mean for them. These *illness representations* and the emotion evoked alongside shaped women's risk perceptions, including the perceived susceptibility and severity of ESBC. Furthermore, cognitive literature has suggested that events which are associated with negative feelings (such as fear) guide decision-making with the intent being to minimize such negative feelings and fears (Finucane et al., 2000).

Subjective susceptibility and severity alone is not sufficient for producing a health-related behaviour, rather, an individual must weigh this *perceived threat* against both *benefits* and *barriers* (costs) of undergoing that behaviour (Rosenstock, 1974). For our patients, the potential benefits of undergoing mastectomy greatly outweighed the potential costs. Women believed there was a direct relationship between leaving breast tissue in the affected breast and the development of negative sequel subsequently resulting in death. This belief translated into an overestimated benefit offered by UM+/-CPM. Specifically, patients believed that choosing to undergo BCT would have resulted in a recurrence and 'spread' of their breast cancer whereas mastectomy(ies) eliminated all likelihood of these events. The beliefs around BCT were frequently shared as being either personally witnessed, or recounted through other women's shared narratives, regretting BCT in the face of disease



progression. Patients believed by undergoing UM+/-CPM they would '*never have to go through this again*', preventing any negative sequelae and ensuring they would survive their ESBC. In contrast, patients underestimated the costs/barriers to undergoing mastectomy. The only barrier experienced by patients during their decision-making process was that of the surgeon dissuading their choice for more extensive surgery (particularly UM+CPM). A barrier which patients overcame through their the beliefs expressed around their own *self-efficacy*, and knowingly seeking out family and friends who would support her irrespective of the treatment decision made, ultimately facilitating their choice for UM+/-CPM. Despite women not perceiving any barriers to UM+/-CPM, the women in this study frequently experienced post-operative and long-term concerns including chronic pain, changes in/ loss of skin sensation, and body-image disturbances. Ultimately women's choice to undergo UM+/-CPM was a response to the meaning women attributed to a diagnosis of ESBC; meaning which had been shaped by personal narratives and previous experiences, stories of suffering and death which resulted in fear, anxiety and overestimated risk perception.

The findings from this research are in-keeping with what has been previously described in the literature. A survey conducted by Nold et al. (2000) demonstrated that the fear of cancer was the most influential reason for women's choice for UM rather than BCT. In studies examining women's decision-making for UM or BCT, Collins (2009) described with each point increase for the value 'peace of mind', patients were two times more likely to undergo UM. The belief in 'a chance for cure' has also been reported to be powerful predictor of patient's choice for UM (rather than BCT) (Smitt & Heltzel, 1997). A survey conducted by Stafford et al. (1998) also demonstrated that fear of recurrence was the most influential factor in a patients' choice to undergo UM rather than BCT. Furthermore, in Stafford's (1998) survey, 93% of all ESBC patients believed that 'cutting it off' or 'ridding self of the breast' is a better, more complete operation. While many of these studies were conducted around the time that BCT was first gaining acceptance as the mainstay of surgical treatment for ESBC, the reasons cited for women's choice for UM are not unlike those expressed by the women in this study. Recent surveys conducted by Rosenberg et al. (2013) and Hawley et al. (2014) have demonstrated similar findings, reporting that women choose UM+CPM due to fear of recurrence. Rosenberg et al.'s (2013) survey demonstrated that women overestimated the likelihood of developing a CBC by 2-4 times. Similarly, Hawley's (2014) study has demonstrated that those women who underwent CPM were significantly more worried about their breast cancer than those

who chose UM or BCT . A study conducted by Abbott et al. (2011) demonstrated that women with non-high risk ESBC estimated their risk of recurrence to be 38.7% and risk of developing a CBC 31.4% over the next ten years, rates of a CBC which are only in keeping with women who have a known BRCA mutation. Interestingly Partridge et al. (2008) demonstrated that in women recently diagnosed with DCIS, level of anxiety was the factor most strongly associated with the greatly overestimated risk of DCIS recurrence, developing an in-situ breast cancer, and distant metastasis. Interestingly, most women surveyed in Rosenberg's (2013) study correctly identified that a women with ESBC was more likely to die from something other than breast cancer, yet almost all women ranked a desire to improve their survival as the reason for choosing CPM. Despite women indicating on the survey that undergoing CPM does not improve survival, fear of developing a CBC, and the desire to extend their life, was the most common reasons for choosing a CPM (Rosenberg et al., 2013). This disconnect was similar to the findings presented here, despite patients reporting being informed that the choice for mastectomy(ies) did not impact survival, they believed that by undergoing UM+/-CPM they had eliminated their risks and increased their chances of surviving ESBC. Understanding how fear and treatment beliefs shapes women's decision to undergo UM+/- CPM is important as will facilitate informed decision-making by enabling improved discussions around surgical care between health-care providers and patients, this is further discussed in section 7.7.

## 7.4 The role of the surgeon

Despite previous literature having demonstrated that the procedure recommended by the surgeon is frequently the treatment that women undergo, there have been very few studies exploring the role of the surgeon and surgical recommendations in the context of the increasing mastectomy rates. To gain an understanding of the surgical consultation, and the intertwined surgeons' perspectives on the increasing mastectomy rates, surgeons from both Ontario (where the patients in this study had been treated) and the U.S. (where many of the studies demonstrating increasing mastectomy rates have been conducted) were interviewed. Chapters 5 and 6 describe the findings generated from these interviews.

### 7.4.1 Surgeons' recommendations

In this study those surgeons who practiced at academic and high-volume breast centers noted an increase in rates of UM and notably UM+CPM. This finding is in-keeping with the quantitative literature which has frequently described the increasing rates of UM and UM+CPM at academic centres (Arrington et al., 2009; Ballinger et al., 2008; Jones et al., 2009; Katipamula et al., 2009; McGuire et al., 2009).

With the advent of shared decision-making, it is expected that a treatment consultation discusses of all the information necessary for patients to understand their disease, and the available treatment options including the benefits, harms, limitations and alternatives (Elmore, Ganschow, & Geller, 2010). Surgeons in this study discussed such information, describing both BCT and UM as equivalent options for the treatment of ESBC which result in the same long-term survival, the advantages and disadvantages of BCT and UM, the need for RT in women who undergo BCS, and the unchanged (potential) need for adjuvant chemo and hormonal therapy with either BCT or UM. In addition, many surgeons expressed that for those patients who are suitable candidates, BCT is the preferred surgical treatment. Many surgeons felt that BCT provided equivalent outcomes to UM while being a less invasive procedure, findings which are in keeping with both the literature on BCT, and the current surgical guidelines (Fisher et al., 2002; National Comprehensive Cancer Network, 2014c; National Institute of Health, 1991; Scarth et al., 2002; Veronesi et al., 2002). Provided there were no medical contraindications, Ontario surgeons frequently recommended that women with ESBC undergo BCT. Ontario surgeons demonstrated a clear preference for BCT, and frequently cited both patients' suitability and the role of the Canadian Guidelines when describing their recommendations for BCT. This is not unlike the findings presented by Deber et al. (1987) in a survey study of Canadian physicians providing treatment for ESBC; even with the recent introduction of BCT (in 1987) 73-75% of surgeons preferred less extensive surgery. In contrast, U.S. surgeons frequently did not put forth a direct treatment recommendation. If asked, some surgeons would provide a recommendation for BCT whereas others would leave the treatment decision entirely up to patient choice. As described in section 2.7.2, previous literature has demonstrated that the surgeon's recommendations have been positively correlated with the rates of women undergoing BCT (Lam et al., 2005; Morrow et al., 2009; Nold et al., 2000; Temple et al., 2006). Literature has also described that when no recommendation is put forth, the rates of women undergoing UM are

substantially higher (34-77%) than those who choose UM after receiving a recommendation for BCT (2-23%) (Kotwall et al., 1996; Lam et al., 2005; Morrow et al., 2009; Schroen et al., 2005).

Interestingly, a survey conducted by Nold et. al (2000) examining women's surgical choice (BCT, UM or UM+Reconstruction (UM+R)) demonstrated that the surgeon's recommendation was an influential factor in those patients who decided to undergo BCT. In contrast, those patients who underwent UM or UM+R reported that (despite being the same surgeons), the surgeon's recommendation was of minimal influence in their decision-making, suggesting that not all patients place the same weight on the recommendations provided by the surgeon. Nold et. al. (2000) also demonstrated that those women who chose to undergo UM and UM+R reported 'fear of cancer' as the factor that was most influential in their choice for mastectomy. As previously described in section 7.3 the meaning that women attributed to their diagnosis of ESBC was influential in the choice for mastectomy. Similar to the findings presented by Nold, this study has demonstrated that women's surgical choice for treatment of ESBC was in response to the *perceived threat* of their diagnosis, and was not influenced by the recommendations of their surgeons

In addition, some of the U.S. surgeons who did not directly provide a recommendation felt that they had guided the conversation towards BCT, thereby anticipating that their patients would infer that BCT was the preferred treatment choice. However, it has been described that the patients' and surgeons' perceptions of the surgical discussion may not be the same. Literature examining patients and physicians perceptions of the decision-making process has frequently described substantial discordance between these perceptions. Bruera et al. (2002) conducted a study of breast cancer patients and their surgeons, examining the amount of concordance between the patients' preferred level of involvement in decision-making and the surgeons' perceptions of that preference.

Agreement between the patients' preferences and the surgeons' perceptions only occurred 42% of the time (Bruera et al., 2002). Similarly, a study of cancer patients' desire for information and preferred role in decision-making demonstrated that physicians were only correct in identifying 44% of patients' preferences (Elkin, Kim, Casper, Kissane, & Schrag, 2007). An additional study conducted by Janz et al. (2004) demonstrated that patients and surgeons only correctly agreed upon how involved the patient was in the decision-making process 38% of the time. While these studies are not specific to patient's perceptions of the surgeons' treatment preferences, they do demonstrate that patients' and surgeons' perceptions of the decision-making discussion often vary therefore, it is

reasonable to consider that patients may be unable to predict a surgeon's treatment preference particularly when preferences are implied rather than explicitly stated. Taking this literature together, it is not surprising that given the multitude of factors which influenced patients' decision-making, that neither a direct nor implied recommendation of BCT from the surgeons, was impactful to those women who were requesting UM+/-CPM.

In contrast to the discussion of BCT and UM as surgical options for ESBC, the discussion around UM+CPM was not initiated by the surgeons in this study, as UM+CPM is not a routine treatment option in the non-high-risk patient population. Rather, both Ontario and U.S. surgeons described patients initiating the request for UM+CPM. Ontario surgeons never recommended, nor encouraged the use of CPM in non-high-risk patient population with unilateral ESBC. Rather these surgeons described a tension within the surgical discussion, akin to a 'tug-of-war', when attempting to discourage and dissuade patients from undergoing UM+CPM. In an attempts to dissuade patients from undergoing more surgery than deemed medically necessary, Ontario surgeons described the lack of survival benefit offered by CPM, the increased risk of operative complications, the potential delay in adjuvant treatment should complications occur and overall, suggested to patients requesting CPM that they treat only the index cancer initially. While the U.S. surgeons did not recommend nor endorse UM+CPM as a treatment option in the non-high-risk population, many U.S. surgeons also did not advise very strongly against this request. In contrast to the Ontario surgeons who described actively attempting to dissuade patients from such extensive surgery, many U.S. surgeons described the very limited benefits and potential risks of CPM however, the final decision for UM+CPM was often left to the woman's choice, inadvertently easing the decision for more extensive surgery. Despite the variation in the Ontario andpU.S. surgeons' discussion around UM+CPM, none of the surgeons recommended that non-high-risk women undergo CPM, findings which are in keeping with both the NCCN guidelines and the position statement released by the Society of Surgical Oncology (SSO) (Giuliano et al., 2007; National Comprehensive Cancer Network, 2014c). The SSO is the only surgical society with a position statement around the use of CPM. Both the NCCN guidelines and the SSO position statement indicates that a CPM should be only be considered in women with a unilateral cancer who are at high-risk for developing a contralateral cancer, that being: either a known BRCA or other high-risk mutation, patients with a family history of breast cancer in multiple first-degree relatives and/or multiple successive generations of family members with breast and/or

ovarian cancer (Giuliano et al., 2007; National Comprehensive Cancer Network, 2014c). In addition, SSO does not endorse the use of CPM in non-high-risk patients, with the exception of women in whom surveillance of the contralateral breast would be difficult (Giuliano et al., 2007). However, very few women in this study discussed the need for future surveillance on the contralateral breast as a concern within the decision-making process. While previous studies have described a positive relationship between the surgeons' recommendation and patients' surgical choice, this study did not demonstrate that the surgeons' recommendations were influential in women's decision-making, rather, the surgeons' recommendations had little (if any) effect on the choice for mastectomy(ies).

#### 7.4.2 Physician-Patient Decision-Making Styles

The surgical discussion itself was often one that consisted of a multitude of options, and potentially without a direct recommendation, often leaving the final decision to the patient. Treatment decision-making for ESBC appears to have moved the patient-physician interaction more towards an 'informed' model of decision-making rather than a 'shared-model' of decision-making (Charles, Gafni, & Whelan, 1997; Emanuel & Emanuel, 1992). Charles (1997) defined shared decision-making (SDM) as "the exchange of both information and treatment preferences, by both physician and patient, and agreement by both parties on the treatment". Unlike SDM, informed decision-making (IDM) does not involve both the patient and physician sharing and agreeing upon treatment preferences, rather IDM has been described as the physician providing all the relevant information from which a unilateral decision may be made by the patient (Charles et al., 1997; Joosten et al., 2008). IDM reflects a consumerist approach to health-care, where at the extreme, patients can acquire all relevant medical information through multiple sources including experience, education, and the media (Emanuel & Emanuel, 1992; Haug & Lavin, 1981). After obtaining all of the 'expert' information patients may make their decision unilaterally, without considering the preferences of their physician (Haug & Lavin, 1981; Reeder, 1972). Literature has suggested that those women who chose to undergo UM+/-CPM more often rate themselves as 'active decision-makers', indicating that they would rather make the surgical decision alone, or with limited input from their surgeon. (Janz et al., 2004; Katz et al., 2005a; Nekhlyudov et al., 2005). In a nationwide SEER study of women who chose to undergo UM, Katz et al. (2005a) reported that approximately 80% of women made the decision, alone (41%) or with some input from their surgeon (37%). In addition, women who chose mastectomy indicated that concerns about recurrence was the most influential factor in

their decision-making (Katz et al., 2005a). A study conducted by Nekhlyudov et al. (2005) demonstrated similar findings in women who chose CPM, with 45% of women having made the decision for CPM alone and 37% having made the decision with some consideration for the surgeon's opinion, only 15% reported sharing their decision-making with the surgeon. Additionally, Nekhlyudov (2005) reported that those women who indicated they alone made the decision described more concerns around recurrence (53%) than those women who engaged in SDM (34%). This literature suggests that women who are choosing to undergo UM+/-CPM appear to have moved from away from SDM, a model where both the patient and physician are equally involved in the treatment decision-making and come to the decisions together, and moved towards a model of IDM, where the patient has independently arrived at the treatment decision (after collecting information from a number of sources) independent of the surgeons' recommendations. The findings from this study reflect this literature, as both the surgeons and patients described that the decision to undergo UM+CPM was introduced and chosen by the patients, and not a recommendation by the surgeons. In addition, (as described above in sections 7.3.2 and 7.3.3) patients described turning to multiple sources of information which shaped the *perceived threat* of ESBC independent of the information provided by the surgeon. Patients, being highly self-efficacious, thereby decided the treatment to best manage the threat of their breast cancer, independent of the preferences of their surgeon. In addition, surgeons simply presenting patients a list of treatment options, (including their risks and benefits), while refraining from a direct recommendation, further lends patients to using an informed model of decision-making; as the patients now 'know' everything the surgeon does, and are then able to make their decision independent of the surgeon's preferences and/or recommendations.

#### 7.4.3. Surgical Consultation as Applied to the Health-Belief Model

In contrast to the role of experiential information in shaping patients' risk perceptions, the discussion that the surgeons shared around risk was restricted to the clinical outcomes and based on the evidence that exists in the medical literature. Surgeons described both the potential *susceptibility* and *severity* of ESBC in terms of objective risk. The use of guidelines and surgeons' acceptance of literature in shaping treatment recommendations in breast cancer has been previously documented. A retrospective institute-wide study (22 treatment locations) of all breast cancer patients treated in 2004 reported a 97% compliance with NCCN guidelines for surgical recommendation on breast

cancer treatment (Landercaasper, Dietrich, & Johnson, 2006). A larger state-wide study reported similar findings, 87% of women with ESBC received surgical treatment in accordance the NCCN guidelines (Bloom, de Pouvourville, Chhatre, Jayadevappa, & Weinberg, 2004). Surgeons shared that the known risks of ipsilateral recurrence and CBC are low in non-high-risk women with ESBC; this was felt to be particularly true for those women who will undergo adjuvant chemo and hormonal therapy. Surgeons also described that UM would not impact the development of a CBC nor metastasis, thereby presenting the *benefits* of undergoing more extensive surgery as marginal at best. By undergoing UM+/-CPM rather than BCT, surgeons described no significant decrease in the susceptibility to recurrence, contralateral cancer, and metastasis, nor improvement in survivability. While some surgeons did discuss the *benefit* of symmetry in those women who underwent UM+CPM with reconstruction, the discussion of this benefit was limited. Overall, in women who are suitable candidates for BCT there was felt to be *no substantial benefit* offered by mastectomy, with perhaps the exception of avoiding radiation in women who might feel strongly against it (however as described in section 7.5.3 avoiding RT was not the reason women in this study underwent UM+/-CPM). As the likelihood of developing a CBC in this non-high-risk population is small, surgeons described the benefit of undergoing CPM in this population as nearly negligible.

*Barriers* to undergoing surgical decision-making include the potential disadvantages of the treatment options. While post-operative complications often went unconsidered by the patients, they were always routinely described by the surgeons. Surgeons discussed the potential for chronic pain as well as the potential cosmetic and lifestyle changes that can be associated with UM+/-CPM. In contrast to the patients in this study, the meaning that surgeons attributed to a diagnosis of ESBC has been shaped by evidence-based medicine rather than witnessed experiences and shared personal narratives.

## 7.5 The role of the medical and sociocultural milieu

While the decision to undergo UM+/-CPM ultimately resulted from patients' choice, a number of external factors have the potential to shape both the surgical discussions and the meaning that patients' attributed to their diagnosis and treatment options. As described in Chapter 5 MRI, reconstruction, legislation and guidelines all inadvertently influenced the choice for



mastectomy(ies). As touched upon briefly in section 7.3.2, and further discussed below, the external environment also plays a role in the social construction of *illness representations*.

### 7.5.1 The role of MRI

MRI has been associated with an increased likelihood of undergoing UM by 1.8 times and CPM by 2.0-2.8 times (King et al., 2011; Miller et al., 2012; Sorbero et al., 2009). However, the increase in mastectomy rates can only be partly accounted for by additional findings on the MRI. As described in Chapter 2, many secondary lesion identified on MRI are often benign, or false positive findings, and therefore do not require excision (Brennan et al., 2009; Lehman et al., 2007). Despite this, it has been demonstrated that once additional disease is documented, women frequently opt for more extensive surgery. Many women with an MRI finding do not complete additional work-up of these findings prior to choosing mastectomy. Miller (2012) demonstrated that 38% of women who underwent mastectomy after additional MRI findings, did so without completing a biopsy to rule-out benign disease, and 31% opted for mastectomy despite a negative biopsy result. However, MRI has also been associated with mastectomy rates which exceed the rates of additional findings (both benign and malignant), and therefore additional findings alone do not entirely account for women opting for UM+/-CPM after completing an MRI (Hwang et al., 2009; Katipamula et al., 2009; Morrow et al., 2011; Solin et al., 2008).

As described in section 7.3.2 the meaning that patients attribute to their disease is shaped in-part by the experience that occurs with the disease itself, including the diagnostic work-up that women undergo. Whether the additional disease was benign, a small secondary malignancy or a false positive, identifying further (potential) disease increased patients' fears around their breast cancer diagnosis and reinforced their beliefs about future surreptitious disease. Many of the surgeons in this study also expressed the potential influence that MRI findings had on women's decision for more extensive surgery. Despite surgeons counselling patients on the clinical significance of additional (often benign) findings, these findings heightened patients' fears around the potential for additional '*lesions*' in the breast. These findings are not unique to this study, two systematic literature reviews have demonstrated that anxiety is substantially increased in women who need to undergo further imaging following mammography (Brett, Bankhead, Henderson, Watson, & Austoker, 2005; Metsala, Pajukari, & Aro, 2012). Women demonstrated increased anxiety both immediately after

mammography when further work-up was required as well as long-term, voicing concerns about the potential for future disease (Brett et al., 2005; Metsala et al., 2012). In addition, surgeons in this study described trying to '*undo the impact of those MRI findings*', counselling patients about the need for further investigations (often biopsy), and dissuading against UM+/-CPM. However, surgeons described that many patients choose to forgo further investigations and opt for mastectomy instead.

The positive associations between MRI use and mastectomy rates, challenges the surgeon to take into account the potential limitations when using such imaging tests, as well as counsel patients about such limitations. While many surgeons in this study stated that they try to limit their use of MRI to situations in which they are required, this was not always feasible. Although it was a more frequent phenomenon experienced within the U.S., surgeons described patients having undergone MRI prior to meeting the surgeon. Within the U.S. this was often at an outside imaging facility and therefore occurred outside of consultation with the surgeon. Within Ontario it was often the radiologists who ordered or very strongly recommended the MRI, placing an obligation upon the surgeon to complete this test. Such events remove the potential to allow surgeons to selectively use MRI and frequently prevented surgeons from counselling patients about the potential for additional findings on MRI (and what these findings might mean for the patients). These findings were not unique to this study, a survey conducted by Basset et. al (2008) described that 74% of imaging practices routinely offered MRI to patients diagnosed with breast cancer, 71% of which occurred at outside imaging facilities. Basset et al.(2008) also discovered that over 95% of the time the indication for MRI was to 'delineate extent of disease', despite this not being an indication (as per surgical guidelines) for MRI, nor of any proven benefit with regards to improved surgical outcomes (Houssami et al., 2013). This discordance in use compared to known indications, is likely reflective of the differences in the surgical and radiological guidelines for MRI use in ESBC. The surgical guidelines state that MRI use in the diagnosis of ESBC should be limited to: the delineation of suspicious findings which are not well seen on other imaging, the presence of axillary disease with an occult primary cancer on other imaging, and establishing the extent of disease only if it cannot be assessed with other imaging (The American Society of Breast Surgeons, 2010). In contrast, guidelines produced by the American College of Radiology (2013) state that the non-cancerous breast should be screened with MRI in all women with a diagnosis of breast cancer, and MRI should

be used to assess extent of disease particularly with regards to the fascia. Comparing these guidelines, the American College of Radiology provides much broader considerations, under which every woman diagnosed with ESBC would be a suitable candidate. In addition, the American society of breast surgeons MRI guidelines state “The decision to use breast MRI as an adjunct to the evaluation of patients with breast cancer should be made by the physician and the patient after joint consideration of the benefits as well as the risks, such as frequent false-positive results. Well-prepared (informed) patients suffer less distress when false-positive findings necessitate additional biopsies or prolong the pre-surgical workup”; supporting this study’s findings that an MRI completed prior to the discussion with the surgeon has the potential to influence patient’s *illness representations* and choice for surgery beyond the consultation process.

### 7.5.2: The Role of Symmetry and Reconstruction

As described in Chapter 2 reconstruction rates have also been positively associated with increasing mastectomy rates. While this is true for both women undergoing UM and UM+CPM, the association has been most notable for women undergoing UM+CPM (Albornoz et al., 2013; Chung et al., 2012; Damle et al., 2011; King et al., 2011; Stucky et al., 2010; Yi et al., 2010). While such studies are predominately statistical correlations and therefore unable to describe to what extent the capability to undergo reconstruction was influential in women’s choice for CPM, the authors argue that the introduction of nipple-sparing mastectomies and improvements in reconstruction techniques, may in-part influence the decision for CPM. This study has also demonstrated a similar correlation with the majority of women who underwent CPM having also undergone immediate breast reconstruction (IBR), whereas the minority of women who underwent UM also underwent IBR (Table 3, Chapter 4).

The findings from this study elucidate, to some extent, the relationship that might exist between reconstruction and women’s choice for mastectomy. Some of the women in this study described initially considering UM for treatment of their ESBC, yet ultimately underwent UM+CPM as they felt they would have improved symmetry and balance. While the concept of symmetry (breasts of similar size, shape and location) and reconstruction are closely related, the role of symmetry in the choice for mastectomy has not been well-described in the literature. Symmetry may be achieved through UM+CPM and reconstruction of both breasts, however this is not the only approach to

achieving symmetry. Symmetry can also be achieved through bilateral mastectomy (without reconstruction), and unilateral mastectomy with reconstruction and balancing procedures (augmentation or reduction) on the non-cancerous side. Some of the women in this study shared that they had been informed that symmetry would be best achieved if both breasts were removed and reconstructed, rather than trying to ‘*match*’ the reconstruction to the natural breast. This information was often learned through the consultation with the reconstructive surgeon, but occasionally women learned of these concepts from family members who may (or may not) have undergone reconstruction and/or networking with other women who had been treated for breast cancer. These findings were also shared by the surgeons in this study. While not experienced by all the surgeons, a notable number (from Ontario and predominately the U.S) stated that it was not unusual for a patient who had chosen UM to be referred to the reconstructive surgeon and return requesting both UM+CPM. While the role that the reconstructive surgeon may play in the decision-making process for UM+/-CPM has not been well described, a survey study has suggested that plastic surgeons were more likely to recommend bilateral mastectomy compared to general surgeons in a setting where the surgeon deemed the patient was at higher risk of recurrence (Houn et al., 1995).

In addition, the general surgeon’s discussion of treatment options may unintentionally shape a woman’s choice for reconstruction (with mastectomy). In this study Ontario surgeons frequently only discussed reconstruction in those patients who were already considering undergoing a mastectomy, this was particularly true in centres where IBR was not available. In contrast, nearly every U.S. surgeon described reconstruction as part of the initial treatment options for ESBC in the initial consultation, those being: BCT, UM or UM+R. In a nation-wide survey Alderman et al. (2008) found that patients with ESBC who had discussed reconstruction options at the initial consultation were four times more likely to choose UM. Also, a nation-wide study examining patterns of care in IBR demonstrated that women undergoing IBR were twice as likely to have the unaffected breast removed and complete bilateral reconstruction compared to those women who underwent UM and did not undergo reconstruction (Joslyn, 2005).

The differences in Ontario and U.S. surgeons’ discussions of reconstruction may be reflective of the differing access to immediate reconstruction. Access to immediate reconstruction is not widely available across Ontario and the majority of reconstruction performed is delayed (Platt, Baxter, &

Zhong, 2011). Between 2002 and 2008 reconstruction rates within Ontario were 23.3%, with only 11.7% performed as IBR (Platt, 2013). In addition, it has been documented that there is significant variation in access to reconstructive surgeons across Ontario with more than half the counties (55%) having very low or low access to a surgeon, and only 26% of the counties having high access (Platt, 2013). Interestingly, Platt et al. (2013) also documented that women who were motivated to undergo IBR would travel to the high access counties, demonstrating the role of patient *self-efficacy*; this phenomenon was also experienced by Ontario surgeons practicing in an areas with low access to IBR. In contrast, U.S. rates were reported as high as 25% for immediate reconstruction in nationwide studies, and 42% across a network of tertiary care centers, with 95% performed as IBR. (Christian et al., 2006; Reuben, Manwaring, & Neumayer, 2009).

The women in this study who did decide to undergo reconstruction felt that they would improve upon the post-mastectomy image they held of themselves, and many women referred to this as returning to '*normalcy*'. By undergoing reconstruction women felt that they could '*get back to normal*' or '*become normal again*'. Constructing the post-mastectomy body as 'abnormal' and restoring the body to 'normal' by having two breasts (possibly through reconstruction) has been previously described in explorations of the meaning given to the post-surgical body (Crompvoets, 2003; Manderson, 1999). Crompvoets' (2003) research demonstrated that many women did not feel that they could 'become normal' without having two breasts. While the majority of our patients who underwent CPM also underwent IBR, this was not true for women who underwent UM, as the majority of women who underwent UM did not undergo IBR. When describing why they had not undergo reconstruction some wanted to avoid additional surgery (demonstrating that at least for some of our patients '*normalcy*' was not defined by having two breasts), while others had difficulty gaining access to a reconstructive surgeon at the time this study was conducted.

While undergoing reconstruction was seen by many women as way of improving body-image, (through the construction of normalcy in their post-mastectomy bodies) it must be stated that this was only seen as an additional benefit in the decision-making process for mastectomy. All women shared that the reason for UM+/-CPM was the desire to control their cancer and eliminate the threat posed by ESBC, concerns around symmetry was secondary to fear of recurrence and CBC. Our findings are in keeping with a survey conducted by Nold et al. (2000) examining those factors

influencing women's choice for BCT or UM. Women who chose to undergo mastectomy indicated that fear of breast cancer was the most influential factor in their surgical choice; this was true even of women who underwent UM+R (Nold et al., 2000). An additional, although secondary, concern of those women who underwent UM+R was around cosmesis (Nold et al., 2000). Nold (2000) states that women's choice for UM+R was 'a more complete procedure (as compared to BCT) while allowing preservation of body image', not unlike this study's findings. Those women who decided upon UM+CPM after considering symmetry described it as an '*added bonus*', with the removal of all potential threat (by choosing UM+CPM and removing both breasts) and return of the normal (now unthreatened) body through the addition of reconstruction. While reconstruction was always viewed as an additional benefit, undergoing additional surgery was never perceived to have any costs (barriers) associated with it, with the exception of the few women who were waiting for delayed reconstruction and had struggled with their self-identity as being 'abnormal' in the interim.

### 7.5.3 The Role of Radiation

Much like the role of reconstruction, the role that radiation played in women's decision-making for mastectomy(ies) was secondary to the meaning women attributed to a diagnosis of breast cancer, and the desire to control the '*overwhelming threat of breast cancer*'. As described in Chapter 2, multiple studies have demonstrated women had preferentially undergone UM (rather than BCT), in-part due to the desire to avoid RT on account of fear of radiation (Benedict et al., 2001; Collins et al., 2009; Elward et al., 1998; Nold et al., 2000; Stafford et al., 1998). However, these studies have also demonstrated that avoidance of RT (and the associated concerns), was always a secondary reason for choosing UM, with the primary reason being fear of the cancer itself, including the fear of recurrence (Benedict et al., 2001; Nold et al., 2000; Stafford et al., 1998). Patient's reported that in addition to avoiding radiation, undergoing UM (more importantly) provided a higher chance of cure and better 'peace of mind' (Benedict et al., 2001; Collins et al., 2009). While these studies were examining women's choice to undergo UM rather than BCT, the findings are in-keeping with the decision-making of the patients in this study who underwent both UM and UM+CPM. The majority of women in this study did not discuss the need for RT with breast-conserving surgery as a substantial consideration in their decision-making process, however, a few of the women did describe the potential of avoiding radiation as an *additional benefit* to mastectomy. Of those who did discuss the additional benefit of avoiding RT, all but one woman, did so out of concerns resulting

from experiential knowledge. Much like previous experiences with family and friends shaped the meaning of a breast cancer diagnosis, having witnessed loved ones suffer side-effects from radiation shaped the meaning of radiation treatment. However, all women uniformly voiced that concerns around the side-effects of radiation was not the primary reason for choosing UM+/-CPM rather, the fear women expressed around their breast cancer diagnosis was the primary concern in their decision-making for more extensive surgery.

#### 7.5.4 The role of legislations and guidelines

Legislations and guidelines indirectly influenced women's choice for mastectomy(ies) by inadvertently shaping the surgeon's discussion of treatment options. This phenomenon was elucidated by comparing and contrasting the surgical discussions presented by Canadian and U.S. surgeons. Canada and the U.S. have similar guidelines for the surgical management of ESBC; both have been derived from the original NIH consensus statement and subsequently updated to reflect the advancing clinical evidence. (National Comprehensive Cancer Network, 2014c; Scarth et al., 2002). Observance of these guidelines was demonstrated by all the surgeons in this study, who described both BCT and UM, as well as their respective advantages and disadvantages. However during the consultation for ESBC, Ontario and U.S. surgeons differed in both the timing of the discussion on reconstruction and in putting forth a treatment recommendation. These differences are in-part reflective of the differences in regulation around the surgical discussion in Ontario and the U.S.

Despite the RCTs in the early 1980's demonstrating survival equivalence between UM and BCT (Fisher et al., 1985a; Veronesi et al., 1981), the results of these trials were not equally adopted (Harris et al., 1986; Nattinger et al., 1996). In response to the unequal uptake of BCT, U.S. state laws, called 'alternative therapy laws', first appeared in the early 1980s mandating surgeons describe all of the treatment options available for ESBC (Nayfield et al., 1994; U.S. Department of Health and Human Services, 2008). While the statutes vary in the extent to which they direct the surgical discussion their original intent was the same, to increase the adoption of BCT. 14 of the 20 states with alternative therapy laws also explicitly require that reconstruction be discussed when presenting the 'alternative therapies' (Nayfield et al., 1994). In addition to the alternative therapy laws, the U.S. has also passed the 'Women's Health and Cancer Rights Act' in 1998, ensuring that women who

underwent mastectomy would also have access to reconstruction and balancing procedures via their insurance plans ("Congressional Record," 1998). Similar laws mandating health insurance coverage of reconstruction, and any required balancing procedures on the unaffected side, have also been passed within every U.S. state. While these laws pertain solely to the affordability (and not the need to inform), they have allowed greater access to reconstruction (Yang et al., 2013). A U.S. nationwide study examining reconstruction rates in women who underwent UM, documented rates of 12.9% at the time of implementation of this Act, and 34.6% a decade later (Yang et al., 2013). Another U.S. nationwide study documented a similar pattern, with rates of reconstruction increasing by 5% per year between 1998 and 2008, increasing from 20.8% to 37.8% of all patients who underwent UM (Albornoz et al., 2013). In addition, the "Breast Cancer Patient Education Act of 2012", if passed, will federally mandate that surgeons inform women of their reconstructive options. In contrast, no such provincial or federal laws exist within Canada. Rather, Canadian surgeons are solely guided by the Canadian Surgical Guidelines which state that "BCS and radiotherapy is generally recommended. In the absence of special reasons for selecting mastectomy" (Scarth et al., 2002). The differences in governing bodies are in-turn reflective of the differences in the Ontario and U.S. surgical consultations. Ontario surgeons, while describing both UM and BCT, frequently recommended that women with ESBC undergo BCT, which appears in keeping with Canadian guidelines. In contrast, U.S. surgeons often refrained from a direct recommendation but did present all treatment options including reconstruction (BCT, UM, UM+R +/- balancing procedures), a consultation more akin to the 'alternative therapy' legislature. As described in section 7.5.2, with regards to the discussion around reconstruction, Ontario surgeons presented this discussion only after a patient was considering mastectomy (UM or UM+CPM), whereas U.S. surgeons often introduced reconstruction as part of the initial treatment discussion. This finding was similar to a study conducted by Stafford et al. (1998) which demonstrated that 74% of surgeons discussed reconstruction even prior to a definitive treatment decision being made. While the surgeons' approach to the consultation process is multi-factorial, some of the surgeons in this study referenced both legislature and guidelines as influential in communicating the treatment options for ESBC. With legislation having shaped surgeons' discussion of multiple treatment options, when without a direct recommendation, leaves the final decision entirely to the patient.



### 7.5.5. Social construction of breast cancer

For the women in this study the meaning that they attributed to a diagnosis of ESBC was largely shaped by their previous cancer experiences with friends and family, or through the narratives shared by other women in the breast cancer community (as described above in section 7.3.2). However some of the patients, as well as the surgeons, in this study also described the larger socio-cultural role in shaping *illness representations* of breast cancer. While not discussed by the majority of participants, both surgeons (Canadian and U.S.) and patients occasionally mentioned local or national celebrities who had undergone treatment for breast cancer. Of those women who did mention such notable figures, they also described being aware of the surgery these women underwent and how ‘*normal*’ they appeared after their treatment. Similarly, some surgeons described answering patients questions around celebrities’ treatments, particularly those who underwent UM+/-CPM+/-R, and attempting to clarify that the breast cancer which that celebrity had (and therefore the reasons for undergoing mastectomy) may differ from the patient’s. While none of the women in this study, nor the surgeons, directly attributed the choice for UM+/-CPM as a result of celebrities’ treatments, the role that the media may have on sociocultural meanings should not be completely overlooked.

Literature has demonstrated that media representations and lay literature can shape sociocultural representations of breast cancer. In their extensive reviews of media representations and surrounding literature both Thorne & Murray (2000) and Lantz & Booth (1998) describe the effect of the media on shaping sociocultural meanings of breast cancer. As described by Lantz (1998) such meanings include risk narratives shaping breast cancer as, ‘an out of control disease’ ‘an insidious disease’ that can affect ‘even the young’, and thus inciting urgency to treat and a need to prevent further disease. While this literature does demonstrate how narratives shape personal *illness representations* they do not describe the resulting health-related behaviours resulting from such *illness representations*. A U.S. nationwide observational study examined the trend in rates of BCS in relationship to Nancy Reagan’s public (and debated) decision to undergo UM for treatment of her ESBC in 1987. Nattinger et al. (1998) demonstrated that the rates of women undergoing BCT was stable in 1986 and most of 1987. However during the last quarter of 1987 and the first quarter of 1988 (which corresponds to the 6 months following Nancy Reagan’s announcement in early October 1987), the

rates of mastectomy increased by 25%, following the transient increase the rates then returned to baseline (Nattinger et al., 1998). During this timeframe there was no other notable medical literature or lay press (outside of the coverage on Nancy Reagan's breast cancer treatment) that called into question the efficacy of BCT, suggesting the influence of celebrity decisions on women's treatment decision-making. Research conducted around mammography screening rates have demonstrated a similar phenomenon. In September and October 1974 both the United States President's and Vice-President's wives (Mrs. Ford and Mrs. Rockefeller) were diagnosed with breast cancer, events which were surrounded by substantial media attention. In a state-wide observational study Fink et al. (1978) described the rates of U.S. women undergoing elective mammography screening increased by 10-15% between October- December 1974, the months immediately following Mrs. Ford's and Mrs. Rockefeller's diagnoses (Fink et al., 1978). More recently described events include the increase in referrals to a UK breast clinic and an increase in mammography in both Australia and the UK, following the public announcement of Kylie Minogue's breast cancer (Chapman, McLeod, Wakefield, & Holding, 2005; Kelaher et al., 2008; Twine, Barthelmes, & Gateley, 2006). In a study examining the referral pattern of general practitioners to a UK breast clinic, Twine et al. (2006) reported a transient increase in referrals by 66% the month following Ms. Minogue's announcement. Studies examining rates of imaging in unaffected women following Ms. Mingogue's announcement reported an increase in mammography rates of anywhere between 25-40% from baseline (Chapman et al., 2005; Kelaher et al., 2008). This increase was reported as early as two-weeks after the announcement and lasted up to 6 months after (Chapman et al., 2005; Kelaher et al., 2008). Chapman's study not only suggests a positive relationship exists between celebrity media coverage and health-related behaviours, but also provides some understanding as to how health-related behaviours might be shaped by media representations. Examining all television news and public service announcements broadcasted in Sydney Australia, Chapman (2005) reported a 20-fold increase in news coverage on breast cancer following Kylie Minogue's announcement (with 13 minutes being devoted to breast cancer in the 13 days preceding the announcements and 147 minutes in the 7 days following). The most dominant messages were those of Kylie's role as a 'fighter' and 'over-coming cancer' (akin to *self-efficacy*) and of her being 'one-of us', messages which may serve in shaping women's illness narratives and *self-efficacy* (as described in sections 7.3.2 and 7.3.3 above) and in-turn influence their health-related behaviour (breast screening in this instance).

It has been documented that breast cancer is over-represented in popular media (Blanchard, Erlich, Montgomery, & Bovbjerg, 2002). An interpretive analysis of breast cancer messages in women's magazines between 1997 and 2002 described *self-efficacy* as a major theme identified across narratives (Gill & Babrow, 2007). Articles encouraged women to seek information, and endorsed patient self-advocacy, including taking responsibility for their medical encounters and taking control of their cancer (Gill & Babrow, 2007). Similarly, a recent examination of the content of U.S. national newspapers and magazines demonstrated that the messages present a strong emphasis on survival (32%) (Fishman, Ten Have, & Casarett, 2010). While the majority of the articles examined discuss aggressive treatment options (57%), few report that aggressive treatments can fail (13%), and less than one-third discuss adverse events associated with treatment (Fishman et al., 2010). Taking these studies together it is possible to understand how the media may indirectly and unintentionally shape the meaning that women attribute to both their diagnosis as well as their understanding of cancer treatment.

The role that the media may play in shaping *illness representations* as it pertains to women currently undergoing decision-making for ESBC is best illustrated through a recent study conducted by Kamenova et al. (2014) examining news coverage of Angelina Jolie's decision to undergo prophylactic bilateral mastectomy. Examining high-quality newspapers in Canada, the U.S and the U.K. in the month immediately following Jolie's public statement, Kamenova et al. (2014) describe how the media portrayed Jolie's decision, as well as information around BRCA, mastectomy and treatment options. It was found that over half of the articles presented Jolie as brave, courageous, empowered and inspiring (Kamenova et al., 2014). Only 32% of the articles discussed the rarity of a woman having a BRCA mutation, and 68% of articles failed to discuss the importance of Jolie being BRCA mutation positive (Kamenova et al., 2014). With regards to surgical management only 18% described the potential complications of mastectomy. Overall Kamenova et al. (2014) found that Angelina Jolie's decision received prominent media coverage depicting a 'courageous decision', but often omitting important medical information (i.e. the rarity of BRCA mutations), in addition, only 10% of articles questioned the potential impact such coverage might have on women's health behaviours. Despite Angelina Jolie being diagnosed with a BRCA mutation (and therefore being from a high risk population for both primary and recurrent breast cancer) Kamenova illuminates the

influence the media may have on shaping women's *illness representations* and the potential (mis)understanding of breast cancer treatment options.

*Illness representations* and *self-efficacy* may also be shaped by the internet, a tool that has been used to both seek out health-care information, as well as a medium for communicating with other individuals affected by cancer (Eysenbach, 2003). It is estimated that upwards of 50% of cancer patients use the internet to seek out some medical information (Chen & Siu, 2001; Ziebland et al., 2004). A qualitative study examining reasons why patients turned to the internet described it as a source of experiential knowledge as well as a way to form social connections with individuals who have had similar experiences (Ziebland et al., 2004). Patients also described using the internet as a tool for learning about treatment options, verifying the medical information received and 'to make sense' of the medical information (Ziebland et al., 2004). Literature reviews of online support groups also describe the high prevalence of information seeking and giving, particularly for women diagnosed with breast cancer (Eysenbach, Powell, Englesakis, Rizo, & Stern, 2004; Klemm et al., 2003). Personal experiences and personal opinions have been reported to account for 80% of the material shared on cancer support sites (Klemm, Reppert, & Visich, 1998). A study examining breast cancer sites described three major dimensions of online support groups, two of which were sharing of information and encouraging personal empowerment (Sharf, 1997). A observational study examined patients' use of the internet and their reported *self-efficacy*; in comparison to non-internet users, internet users scored significantly higher on three *self-efficacy* measures: actively participating in treatment decision-making, asking physicians questions, and expressing their concerns (Bass et al., 2006). In addition, Bass et al. (2006) describe that internet users demonstrated different behaviours than non-users, including preparing questions for their physician, questioning physician's recommendations, and developing a 'partnership' with their physician (Bass et al., 2006). Much like the findings around media, the discussion of the internet in treatment decision-making was variable by both patients and surgeons in this study. While some women did describe using the internet (including blogs and reading personal narratives), there was no single internet source that was described in a notable or influential fashion, rather most women could not clearly recall their internet sources. Similarly, many surgeons reported directing women to reputable internet sources but infrequently described internet information playing more than a minimal role in the surgical consultation. Despite these research findings, a Cochrane review has demonstrated that both planned

media campaigns and unplanned media coverage can translate into altered health-related behaviours. As described above such change in behaviours may be due to changes in *illness representations* (and related treatments) and/or perceived *self-efficacy*. While not elucidated within this research, a future direction of this research could include exploring the role of the media in generating larger sociocultural messages which may be indirectly shaping *illness representations* and influencing treatment related behaviours.

## 7.6.: Exploring women's choice for mastectomy – Expanding upon the Health-Belief Model

The HBM was originally put-forth as a means of understanding health-related behaviours, as applied to this study, that is the decision to undergo UM+/-CPM for treatment of ESBC. As described in section 7.2 a health-behaviour is undertaken when the threat is perceived to be great. A specific behaviour is chosen if it is perceived to remove or substantially reduce that threat and the costs of the behaviour are seen as less than the benefits of that behaviour. Applying the concepts of the HBM to these research findings has demonstrated that women in this study perceived a diagnosis of ESBC as an '*overwhelming threat*' to their future; without removing this threat, women believed they would unavoidably suffer the sequelae of ESBC and death. This research has demonstrated that the choice for more extensive surgery can be understood through the meaning that women attributed to their diagnosis of ESBC (i.e. the *perceived threat*), the *perceived benefit* of undergoing mastectomy, and the *perceived minimal barriers* of choosing UM+/-CPM. However, to truly appreciate what is influencing women's choice for more extensive surgery requires an appreciation of those factors shaping women's health-beliefs and perceptions.

As presented in Figure 11 (section 7.2), Champions' adaptation of the HBM suggests that modifying factors (including: age, gender, ethnicity, socioeconomics and knowledge) shape both disease and treatment beliefs. Women in this study varied across age, ethnicity, and socioeconomic status, however the modifying factor which was influential in women's choice for mastectomy was knowledge, (i.e. *illness representations*), which had been shaped by personal events, witnessed experiences and shared narratives, forming women's risk perceptions. Figure 13 demonstrates the importance of *illness representations* on shaping patients' risk perceptions (the threat they attributed

to a diagnosis of ESBC) and in-turn the choice for UM+/-CPM. While a multitude of factors shaped women's *illness representations* (both the meaning they attributed to ESBC as well as their treatment related beliefs), previous cancer experiences and personal narratives were found to be the most meaningful and influential to the women in this study. While not experienced by all women, delays or difficulties during their own diagnosis also contributed to women's perceptions of the threat of ESBC. Medical information (while often inadvertent) such as that provided by MRI, the reconstructive surgeon and other members of the health-care team also shaped the meaning of ESBC and/or treatment related beliefs. While the information provided through consultation with the general surgeon was often not meaningful in women's perceptions of ESBC, some surgeons were perceived as barriers to be overcome in order to undergo UM+CPM, thereby influencing women's treatment beliefs. While the role of the sociocultural milieu on shaping women's illness perceptions was not greatly appreciated (through this grounded theory study), previous literature has demonstrated that sociocultural representations of breast cancer can surreptitiously shape the meaning society attributes to the disease. Future directions of the research might include better elucidating the role of sociocultural representations of breast cancer on women's treatment decision-making for mastectomy. As discussed above, patients' *self-efficacy* is fundamental in their capability to overcome barriers in their treatment decision-making. This was particularly true for the women in this study who chose UM+CPM despite the discouragement they felt from their surgeons. While *self-efficacy* may be shaped by a multitude of events including: previous personal experiences, through shared identities and larger sociocultural discourses, this was not well elucidated within this study and therefore may also serve as a future research direction.

This study has described those events and experiences which shape the meaning women attribute to both the diagnosis of ESBC and its potential treatment options. Understanding how women's *perceived threat*, as well as beliefs around treatment barriers and benefits, have been shaped is important, as the choice for more extensive surgery is not without potential harm.

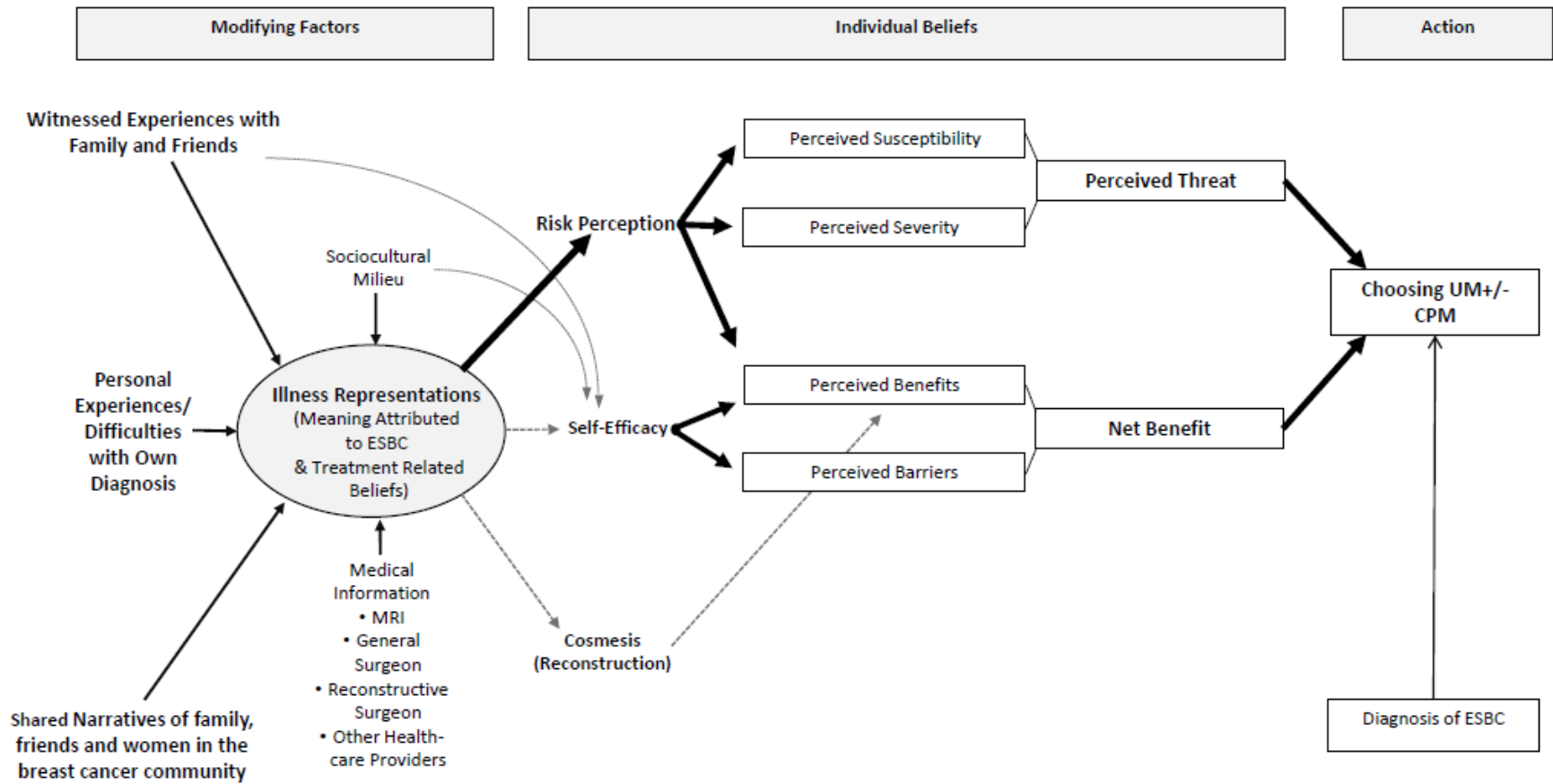


Figure 13 depicts an expanded version of the HBM, reflecting the research findings discussed above

## 7.7 Implications

### 7.7.1 Post-operative and long-term complications

As described in Chapter 2, undergoing UM+/-CPM offers no survival advantage beyond that of BCT. Whether BCT or UM is undergone, with newer adjuvant therapies, the risk of local recurrence are nearly equivalent, and rates of CBC are marginal. Despite no survival benefit and minimal (if any) reduction in further disease, women have been undergoing UM+/-CPM with increasing frequency over the last 5-10 years. This study has demonstrated the influence of *illness perceptions* on the choice to undergo mastectomy. The **‘overwhelming threat’** of ESBC resulted in women choosing to undergo UM+/-CPM to control and eliminate this threat. However the choice to undergo more extensive surgery is not without a cost, while not perceived by the patients at the time of decision-making many women in this study continued to experience ongoing effects from their mastectomy(ies) including chronic nerve pain, changes (decreased) skin sensation, and negatively altered body-image. These findings are not unique to the women in this study, as long-term complications including sensory skin disturbances and chronic pain have been reported in upwards of 50% of surgical breast patients, of which 25%-40% of women report having moderate pain affecting their daily lives, and 5-13% of women experience severe or disabling pain (Brummett, 2011; Gartner et al., 2009; Tasmuth et al., 1995). While post-operative pain is often described as chronic, unchanging and of long duration at the site of the scar or chest wall, it can also present as a burning, aching, lancing or tightness that extends into the axilla, and/or arm (Stevens, Dibble, & Miaskowski, 1995). While pain has been reported in both women who have undergone BCT and UM, retrospective surveys have described that women who undergo UM frequently have a higher severity of pain, and more frequently experience sensory disturbances than those women who have undergone BCT (Gartner et al., 2009; Tasmuth et al., 1995). In addition, higher rates of seroma formation (a known post-operative complication of breast surgery) have been reported in women who undergo UM; such post-operative complications have been positively associated with chronic post-operative pain (Tasmuth et al., 1995). Studies using both institute and nation-wide data have demonstrated that that undergoing CPM doubles the risk of the known post-operative complications associated with UM (Goldflam et al., 2004; Miller et al., 2013; Osman et al., 2013). Minor post-



operative complications including delayed wound healing, infection, minor post-operative bleeding and mild seromas; these complications have been reported in up to 20% patients after mastectomy of the non-cancerous breast (Eck, Perdakis, Rawal, Bagaria, & McLaughlin, 2014; Miller et al., 2013). In addition, major complications including seromas/hematomas requiring surgery, infection requiring hospital admission, tissue necrosis and bleeding requiring transfusion, occurred in 13.9% of patients who underwent CPM, 2.7 times more frequently than patients who underwent UM (Miller et al., 2013). Studies examining re-operation rates have demonstrated that re-operation is required in 4-10% of contralateral prophylactic mastectomies, most frequently due to post-operative complications (Eck et al., 2014; Miller et al., 2013; Zion et al., 2003).

Chronic post-operative pain is of concern as it has been demonstrated to interfere with daily functioning (particularly for those patients who experience severe pain), as well as impact long-term quality of life (Macdonald, Bruce, Scott, Smith, & Chambers, 2005; Stevens et al., 1995). In a study examining persistent post-mastectomy pain nine years after mastectomy, almost half of the initially affected (43%) women reported ongoing pain, resulting in interference with daily activities including lifting, carrying, housework, and exercise (Macdonald et al., 2005). Women with persistent pain scored significantly lower on all measures of quality of life in comparison to those women whose pain had resolved within the first 3 post-operative years (Macdonald et al., 2005). While no studies to-date have examined the rates of post-mastectomy pain in the contralateral breast, a study conducted by Gahm et al. (2010) examined the rates of post-operative pain in high-risk (BRCA positive families) women who underwent elective prophylactic bilateral mastectomy with reconstruction. 69% of patients described ongoing pain and 71% reported discomfort and changes in skin sensation 2 years following their initial surgery (Gahm et al., 2010). In addition, women reported that pain and discomfort were worsened by touch and physical activity (Gahm et al., 2010). 16% of the women in Gahm's (2010) study also demonstrated regret around their decision, most of which was attributed to either ongoing post-operative pain or immediate post-operative complications that required further surgery. While the patient population in Gahm's study differs from the women interviewed in this study (as all women underwent immediate reconstruction, and Gahm's patients were a high-risk population, therefore the meaning attributed to having a BRCA diagnosis likely impacted their decision-making), Gahm's study isn't without merit; it demonstrates the potential for chronic pain in the non-cancerous breast, as well as the regret experienced by

women secondary to long-term pain. A survey conducted by Altschuer et al. (2008) examined satisfaction in women who underwent CPM. Altschuer (2008) demonstrated that while 85% of patients report overall satisfaction with CPM, qualitative assessment demonstrates up to 84% of those who report overall satisfaction experience some dissatisfaction in the areas of body image, sexuality and chronic pain. A similar study by Frost et al. (2011) demonstrated that 20 years after surgery, 90% of women with unilateral cancer who underwent UM+CPM reported being satisfied with their surgical decision. However, when examining the impact of CPM even 20 years after surgery, 45% of women reported ongoing effects, most frequently around appearance (31%), feelings of femininity (24%), sexual relationships (23%) and self-esteem (10%) (Frost et al., 2011). Examining those aspects of body image that were most affected by CPM it was found that women frequently felt less sexually attractive (15%), dissatisfied with their scar (12%), dissatisfied with how their body looked both naked (12%) and dressed (7%), were self-conscious about their appearance (10%), and felt that CPM left them ‘less whole’ (8%) (Frost et al., 2011). A U.S. national survey of women who underwent CPM prior to 1998 demonstrated that only a small proportion of women voiced regret around their decision (6%), however those that regretted their decision most frequently did so because of cosmetic outcomes (39%), and diminished sense of sexuality (22%) (Montgomery et al., 1999). It was also noted that regret was higher in those women who requested CPM, rather than had been recommended CPM by their surgeon (Montgomery et al., 1999). Given the lack of medical benefit and the potential for long-term harm, it is therefore prudent to ensure that a woman’s surgical decision for ESBC is truly informed; that both the risks and benefits are attended to and understood, and that the decision made is not solely in response to the *‘overwhelming threat’ of breast cancer*.

### 7.7.2 Post-operative and Long-term Anxiety

One could argue that while undergoing UM+CPM may not offer a survival benefit, a potential benefit of more extensive surgery may be achieving ‘peace of mind’. In addition to the discussion presented in section 7.3.3 around the potential negative consequences of employing exaggerated control beliefs in an unmodifiable situation, it remains unclear to whether undergoing UM+/-CPM may relieve long-term emotional concerns and anxiety. A recent systematic review has demonstrated that anxiety in women diagnosed with breast cancer is ubiquitous; women who have

received both surgical and adjuvant treatments experience anxiety, with anxiety being highest in women undergoing chemotherapy and lowest in women undergoing RT (Lim, Devi, & Ang, 2011). In the early 1990s when BCT was first gaining acceptance, in hopes of ascertaining to what extent surgical treatment (BCT or UM) might impact post-operative levels of anxiety, two RCTs were conducted. Lee et al. (1992) demonstrated that both pre and post-operative levels of anxiety, while higher in the group of women randomized to UM rather than BCT, were not significantly different (20% vs 15% pre-operative, 21% vs 14% at 3 months post-operatively and 9% vs 3% at 12 months post-operatively). The second RCT conducted during the same timeframe demonstrated no difference in anxiety levels either pre or post-operatively (15-42 months) in women who were randomized to either UM or BCT (Poulsen, Graversen, Beckmann, & Blicher-Toft, 1997). A pseudo-randomized study (women were randomized to BCT or UM when possible, or otherwise underwent UM) reported similar findings, with rates of anxiety being higher in the UM group pre and post-operatively across all time points measured (3, 6, and 9 months); again, while the rates of anxiety were higher in the UM group this difference was not significant (McArdle, Hughson, & McArdle, 1990). Additional observational studies have also demonstrated similar trends, with patients who have undergone UM having higher rates of anxiety both pre and post-operatively in comparison to women who have undergone BCT; however, none of these differences were significant, and all of the studies have demonstrated a decrease in levels of anxiety over-time irrespective of which surgery patients underwent (Fallowfield, Hall, Maguire, & Baum, 1990; Maraste, Brandt, Olsson, & Ryde-Brandt, 1992; Omne-Ponten, Holmberg, Burns, Adami, & Bergstrom, 1992). A long-term retrospective study, conducted 5 years post-operatively, demonstrated no difference in levels of anxiety in women who had undergone UM or BCT and interestingly, similar levels of fear of recurrence between the two groups, irrespective of whether women underwent UM or BCT (Meyer & Aspegren, 1989). While these studies were conducted before the recent increase in mastectomy rates none of these studies have demonstrated that undergoing more extensive surgery notably reduces either immediate or long-term post-operative anxiety. In addition, while the findings were not substantial, many studies reported women undergoing UM had higher rates of post-operative anxiety (not lower), a factor which might be confounded by who chooses to undergo mastectomy.

In contrast to the studies examining anxiety in women undergoing UM, studies have demonstrated a reduction in post-operative anxiety in BRCA positive women undergoing bilateral prophylactic mastectomy (Brandberg et al., 2008; den Heijer et al., 2012). However, the BRCA positive population has a substantially higher breast cancer risk and therefore these findings cannot be applied to the non-high risk population (such as the women included in this study). There have been no studies to date which have examined the rates of pre and post-operative anxiety in non-high-risk women who undergo CPM. However, a recent survey examining women's choice for CPM demonstrated that even after undergoing UM+CPM, 90% of women continue to report ongoing concerns about the potential for cancer recurrence (Rosenberg et al., 2013). In addition, a large statewide prospective study of women with DCIS has demonstrated that patients greatly overestimated the risk of their DCIS returning or developing an invasive cancer (not unlike the fears shared by patients in this study), along with these overestimated risks, women reported high levels of anxiety (Partridge et al., 2008). Women's anxiety was re-assessed at 9 and 18 months following their initial diagnosis and treatment, despite receiving no additional treatment during this time period the rates of anxiety decreased substantially over time (Partridge et al., 2008). Taking these studies together it seems that despite the choice for more extensive surgery an attempt to control the '*overwhelming threat and misperceived risk*' of ESBC, undergoing UM+/-CPM may not entirely alleviate women's ongoing fears. In addition, women's fears may decrease over time irrespective of which surgical treatment that is undergone.

### 7.7.3 Applications using the HBM

As the HBM allows us to understand how beliefs shape treatment behaviour, a change in women's beliefs around the threat associated with ESBC, may prompt women to choose less extensive surgery (particularly those women who chose UM+CPM). Research using the HBM has been described to develop tools with the intent of increasing preventative behaviours such as mammography screening and breast self-examination (BSE) (Champion, 1994b; Umeh & Rogan-Gibson, 2001). Champion (1994b) designed a study examining women's uptake of mammography with and without targeted interventional tools. Patients underwent an initial questionnaire which served to assess their baseline beliefs around the utility of screening mammography as they pertained to the HBM (ex. perceived severity) (Champion, 1984; Champion, 1994b). Women were then assigned to one of four groups:

control, belief-specific intervention (individual counseling based on the assessments of the baseline questionnaires), a standardized information intervention, or both belief-specific and standardized information interventions (Champion, 1994b). Belief-specific interventions included: counseling on risk factors for breast cancer if women scored low on perceived susceptibility, counseling on mortality rates for those who scored low on perceived severity, and benefits and barriers counseling occurred for those scores (around these beliefs) which would impede mammography use (Champion, 1994b). Champion (1994b) demonstrated that use of mammography screening increased by more than twice in women who received belief-specific interventional tools (counseling), in comparison to standard consultation. Mammography use increased most substantially when the belief-specific tools were combined with standard information packages (Champion, 1994b). In another study examining modes of intervention telephone counseling, in-person counseling, and a standardized information letters all increased mammography use; however, in-person counseling along with an information letter had the most notable effect (Champion et al., 2003). A meta-analysis of mammography utilization demonstrated that interventions based on the HBM increased screening rates by 23.6% (compared to usual care), this was greater than interventions based on other behaviour theories or sociological models; in addition, screening effect was greatest when more than one intervention was used, and at least one intervention was delivered interactively (similar to the findings of Champions' (2003) study) (Yabroff & Madelblatt, 1999). Increased uptake of mammography and BSE occurred when women perceived they were highly susceptibility to a diagnosis of breast cancer, the severity of the diagnosis would be grave, and there were potential benefits and limited barriers to screening (Champion, 1994a; Umeh & Rogan-Gibson, 2001). Studies such as those conducted by Champion and Umeh have demonstrated that health-related behaviour changes can occur through the development of tools based on an individual's perceptions with the HBM framework. A future direction of this research would be to develop an ESBC beliefs measurement scale, (similar to Champion's (1994b) study), to identify those women who might choose UM+/-CPM based on the *misperceived risk* of ESBC, the over-estimated benefit and/or the lack of perceived costs of mastectomy(ies). A belief-specific tool such as interactive counseling and a standardized information pamphlet (Champion, 1994b) could then be provided to reshape women's beliefs around the threat of ESBC, and the benefits and barriers of mastectomy; such that a choice for mastectomy does not

stem from an '*overwhelming threat and misperceived risk*', but rather one which is truly informed of both the risks and benefits.

HBM research has also demonstrated that the greatest agreement between patients' treatment behaviours and physicians' recommendations occurs when patients perceived the recommendation had maximal benefits, minimal barriers and substantially reduces the *perceived threat* (Becker, 1985; Cummings, Becker, Kirscht, & Levin, 1982; Kirscht, 1998). While surgeons recommended BCT, patients perceived BCT to offer minimal benefits and would not serve to maximally reduce the threat of ESBC, thus was not considered to be the preferred surgical treatment. Understanding the meaning that women attributed to their breast cancer diagnosis, and the impact of personal narratives on shaping this meaning, suggests that incorporating narratives as a source of information into the surgical consultation may be a useful tool to inform women of the entire spectrum of possibilities for treatment of ESBC, including the risks and benefits of each surgical option. Studies have demonstrated the use of narrative information in conjunction with standard health-care provider information, increased patient knowledge and had a greater impact on practice, than standard information alone (Enkin & Jadad, 1998; Mazor et al., 2007; Perez et al., 2014). A feasibility study examining the utility of videotaped narratives from breast cancer 'survivor' stories demonstrated that the study participants developed a '*shared identity*' with the women in the narratives, making statements such as 'they think a lot like me, they're values are a lot like mine' (Perez et al., 2014). As all of the participants felt that they could identify with the women, they in-turn trusted the women in the narratives and were more inclined to undergo behaviours (such as mammography) which had been discussed in the narratives, and previously recommended by their physicians (Perez et al., 2014). In addition, a nationwide study examining the effects of an online narrative tool demonstrated increased healthcare participation (Wise, Han, Shaw, McTavish, & Gustafson, 2008). A large randomized trial has been conducted comparing patient knowledge and behavioral intents of warfarin use in patients requiring anticoagulant therapy (Mazor et al., 2007). Patients were randomized to either standard medical care or one of three videos, which consisted of either narrative information, statistical information or both narrative and statistical information (Mazor et al., 2007). While all videos resulted in increased patient knowledge and beliefs in the benefit of warfarin, the video with patient narratives had the most notable effect (Mazor et al., 2007). While the use of narrative tools in the patient-physician consultation has been limited to-date, these studies

suggest that there may be a role for narrative tools which illustrate previous patients' experiences with BCT, UM and CPM, complementing the surgical consultation process and modifying patients' misperceptions around the threat of ESBC, and the risks and benefits of more extensive surgery.

In addition, decision-aids (DA) are tools that have been specifically designed to assist with decision-making when there is more than one treatment choice, and each option has benefits and risks that patients may value differently (Goel, Sawka, Thiel, Gort, & O'Connor, 2001). A randomized control trial demonstrated that a DA resulted in improved patient knowledge for surgical treatment options (BCT and UM) in ESBC (Whelan et al., 2004). Patients who were randomized to the DA scored significantly higher in their knowledge questionnaire than those patients who did not receive the DA (Whelan et al., 2004). The greatest improvement was demonstrated around the understanding that survival was the same with UM or BCT, with 78% responding correctly in the DA group in comparison to 58% in the non-DA group (Whelan et al., 2004). While no DA that exists to-date includes information on CPM in the non-high risk population, developing a DA that includes all surgical options (BCT, UM and CPM), incorporating both positive and negative patient narratives may present women with a fuller understanding of both the risks and benefits of all surgical treatments (Bekker et al., 2013; Shaffer et al., 2014; Ubel et al., 2001). Given that potential for long-term complications (particularly in those women who undergo UM+CPM), the choice to undergo mastectomy needs to be accurately informed about the threat of ESBC, the risks and benefits to BCT, UM+/-CPM, and not based solely on the misperception that more surgery equates to controlling the threat of ESBC.

#### 7.7.4 The Patient-Physician Relationship

Studies examining treatment decision-making using the HBM have demonstrated that both patients' beliefs and the patient-physician relationship can impact the treatment decision. Within the HBM the patient-physician relationship is also a potentially modifying factor in treatment behaviour (Becker, 1974). Patients are less likely to agree with physician recommendations if a tension exists (thereby decreasing trust) in this relationship (Becker, 1974; Davis, 1968), and patients are more likely to acknowledge treatment recommendations when they are satisfied with the initial contact (Francis, 1969). This research study has highlighted another area which can be improved upon during the decision-making process for ESBC, that being, the patient-physician encounter. While patients and

surgeons attributed different meanings to the diagnosis of ESBC, these meanings were not explored during the consultation process. As described in chapter 6, surgeons acknowledged that the meaning women attributed to a diagnosis of ESBC was largely shaped by witnessed experiences and shared personal narratives however, the impact that this meaning had on patient's decision-making went unattended. Rather, the surgeons in this study described the risks of ESBC, and the risks and benefits of BCT, UM and CPM in terms of evidence-based discussions, discussions that were not meaningful in terms of patients' *illness representations* and their decision-making. In her study exploring women's understandings of breast cancer in high-risk families Bernhardt (1997) illustrates how patient's knowledge is shaped by narratives and anecdotes which may be factually incorrect. Bernhardt (1997) argues that health-care providers must be aware of what is considered important and relevant to the patients, and that disclosure of factual information alone by the health-care provider does not ensure understanding. Findings from this study would go on to suggest not only is factual information unable to 'ensure understanding' it also does not 'un-do' the meaning that has been attributed to ESBC.

Despite personal experiences and narratives greatly influencing our patients' decision-making process, patients did not readily share what was most concerning for them, that being, witnessed experiences which shaped fears around their perceived inevitability of suffering a local recurrence, a new CBC and subsequent death, and surgeons were often reluctant to ask. These findings are not unique to this research, rather this phenomenon has previously been described in the literature (Detmar, Aaronson, Wever, Muller, & Schornagel, 2000; Hack et al., 2005). An institute-wide study examining patient-physician communication patterns demonstrated that while 90% of oncology patients wished to discuss their feelings and emotional concerns with their physician, only 25% did so, and that was in response to the initiation of such conversations by the physician (Detmar et al., 2000). However, the physicians in Detmar's (2000) study reported that they do not routinely initiate conversations around patients' emotional functioning, demonstrating an inherent gap in patient-physician communication. A qualitative study examining the behaviours of patients and physicians during the clinical encounter demonstrated that patients most frequently raise their concerns and fears in the midst of narrative information (Beach et al., 2005). However, physicians frequently failed to attend to and /or recognize the concerns contained within such narratives, often inadvertently dismissing or constraining such narratives; thereby limiting communication with



patients around that which may be most meaningful in shaping their illness representation (Beach et al., 2005). Those physicians who did recognize such concerns were only minimally receptive, moving the discussion away from the patients emotional concerns (Beach et al., 2005). A hospital network study conducted in the UK has also demonstrated that 35% of the time physicians misclassify a patients' emotional distress, frequently underestimating the level of distress a patient was experiencing (Fallowfield, Ratcliffe, Jenkins, & Saul, 2001). Taking these research findings together, it is possible to understand how such a disconnect might have occurred for the women in this study and their treating physicians, with surgeons actively discouraging patients from undergoing CPM and recommending BCT, despite patients requesting UM+/-CPM.

It has also been described how events during the diagnosis (such a difficult or delayed workup) can weaken a patient's trust in the diagnosis, as well as negatively impact the patient-physician relationship (Becker, 1985; Leydon, Bynoe-Sutherland, & Coleman, 2003; Schaepe, 2011). However, literature has demonstrated that even after a difficult diagnosis patients' trust can be increased through effective patient-physician communication (Fiscella et al., 2004; Hillen, de Haes, & Smets, 2011; Thomsen, Pedersen, Johansen, Jensen, & Zachariae, 2007). Specifically, those patients who felt that their disease experience had been explored by their physician reported improved trust in the patient-physician relationship (Fiscella et al., 2004). In addition, it has also been demonstrated that optimal physician communication decreases patients' emotional concerns and in-turn modifies decision-making behaviour (Fiscella et al., 2004; Henman et al., 2002). A qualitative study examining those factors that were influential in women's decision-making for cancer treatment found that the quality of the patient-physician relationship and 'feeling cared for', was as influential as the medical information received during the patient-physician encounters (Henman et al., 2002). Women who felt that they 'hadn't been listened to', struggled to trust both their oncologists as well as the treatment recommendations. In contrast, those women who felt that they had been 'listened to' and perceived their physician as empathetic and caring, often underwent the treatment recommended by their oncologist (Henman et al., 2002), demonstrating that role that physician communication styles may play in patient's decision-making. Therefore, the disconnect that existed between patients and the surgeons in this study, can be improved upon by identifying and employing physician behaviours which promote the discussion of patients' fears and concerns. Research has identified physician behaviours which promote the discussion of patients' emotional

concerns, increase trust in the patient-physician relationship, and overall result in favorable patient-physician relationships. Such behaviours include open directive questions, clarifying non-verbal cues, summarizing patients' statements, allowing patients to discuss their main concerns without interruption, and general empathetic statements (Becker, 1985; Harris & Templeton, 2001; Maguire et al., 1996; Simpson et al., 1991). In contrast, reassurance, leading questions and focusing on the physical aspects of the diagnosis decreased the communication of patients' concerns (Beach et al., 2005; Maguire et al., 1996). By improving physician communication we can open the discussion to include those concerns which are shaping patients' choice for more extensive surgery.

## 7.8 Conclusion

This research is the first qualitative study to thoroughly describe why women are now choosing UM and UM+CPM for treatment of ESBC. Applying the HBM has provided an understanding of how disease and treatment-related perceptions shape the decision to undergo more extensive surgery. These findings have implications for both future women undergoing surgical decision-making for ESBC, as well as their health-care providers. As the sequel and survivability of ESBC are not controlled by undergoing more surgery, attempting to achieve control over the '**overwhelming threat**' of ESBC may have heightened deleterious psychological and physical outcomes for patients. While it is not to say that women should not be able to choose their surgical treatment, this study has demonstrated that the choice for mastectomy for these women stemmed from a *misperceived risk*. Understanding of how women have come to form their perceptions around a diagnosis of ESBC, and their treatment beliefs' is important as it will facilitate informed decision-making, ensuring that the choice for mastectomy is truly informed about the threat of ESBC, the potential risks and benefits of UM+/-CPM and not solely in response to fear, and hopes to control the '**overwhelming threat**'.

While it cannot be assumed that the patients in this study are representative of all women receiving a diagnosis of ESBC, I set out to describe the experiences that resulted in the choice for mastectomy in the local patient population. Through purposive sampling we ensured that our women were diverse in age, ethnicity, and level of education. In addition, the patients' variation in age and level of education were reflective of the demographic variation which has been reported in the quantitative literature demonstrating increased mastectomy rates (Arrington et al., 2009; Mahmood et al., 2013; Tuttle et al., 2007; Yao et al., 2010). Similarly, the surgeons varied in location of practice (academic

and community, urban, suburban and rural), length of practice, extent of training and gender. The surgeons in this study were reflective of both the demographics which have been reported in the quantitative literature associated with the increasing mastectomy rates (Arrington et al., 2009; Reitsamer et al., 2008), and the variation that exists for breast surgeons in North America. Irrespective of the individual demographic features of the women in this study, the reasons for women choosing mastectomy were consistent. Their choice was rooted in disease perceptions which had been shaped by those factors influencing individual *illness representations*. Those modifying factors which shaped women's *illness representations*, particularly previous witnessed experiences and shared narrative information, were common to all the women in this study. Therefore these findings may be applicable to women across various ages, ethnicities and levels of education within urban settings who are considering mastectomy as their treatment choice for ESBC. In addition, understanding the phenomenon of increasing mastectomy rates from a health-behaviour model such as the HBM not only allows for a rich appreciation for those factors that are influential in the choice for mastectomy, but also allows the knowledge gained from this research to be applied to other research settings. Placing these research findings within the well-developed constructs of the HBM allows the findings from this research population to be generalizable to other populations or health-care settings where the modifying factors such as narratives and experiences might result in the perception of ESBC as an '***overwhelming threat***'.

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## Appendices

### Appendix A: Letter of Invitation to the Study – Patient Participants

Dear Potential Participant,

You are being asked to consider taking part in a research study entitled: *“Choosing Mastectomy: A Qualitative Exploration of the Increasing Mastectomy Rates in Women with Early-Stage Breast Cancer”*

As a full time Graduate Student in the Department of Health Policy Management and Evaluation at the University of Toronto, Dr. Andrea Covelli is currently conducting research under the supervision of Dr. Baxter (St. Michael's) and Dr. Wright (Sunnybrook Health Sciences Centre) on surgical decision making in women with early stage breast cancer.

Our goal is to explore why women are choosing the surgeries they do. In particular, we want to understand which factors are important and influence women's preference for surgery. We will be interviewing 30 women across the Greater Toronto Area, and hope to interview six women who have been treated at St. Michael's Hospital.

As a woman who has been recently treated for breast cancer and has undergone surgery, your experience and perspectives provide key information. We would like to invite you to consider taking part in an one-on-one audio taped interview. This interview will take approximately 60 minutes to complete.

#### ***Your Involvement***

You will receive a phone call from the Graduate Student (Dr. Covelli) approximately 2 weeks after receiving this letter to discuss the study and address any questions you may have. We understand that we are asking very sensitive questions, and that this survey may not be coming to you at the best time.

We want you to know that you have two options:

#### **1. If you are not interested in participating.**

If, after reading this brief description, you are not interested in participating, please either:

- Contact Dr. Andrea Covelli at 416-886-6810, or [andrea.covelli@utoronto.ca](mailto:andrea.covelli@utoronto.ca), or by returning the included form in the postage-paid return envelop
- or
- Advise the researcher at the time of the follow up phone call (which will be in approximately 2 weeks after receiving this letter).

If you do not want us to call you regarding this study, please let us know by contacting Dr. Andrea Covelli at 416-886-6810 or [andrea.covelli@utoronto.ca](mailto:andrea.covelli@utoronto.ca). We will make sure you are not contacted again regarding this study, and we thank you for your time.

#### **2. If you are interested in participating.**

If you are still interested in participating, you will find enclosed in this package:

- One (1) copy of the Consent Form, that describes the study in detail;
- One (1) copy of the form indicating interest in the study; and
- A postage-paid return envelope.

### What do you need to do?

Please carefully read the **Consent Form** and call us if you have any questions. The Master's Student will call you in a couple of weeks to review the goals and method of the study and would be happy to address any other question or concerns you may have. She will arrange an in-person interview arranged at a time convenient to your schedule, and will last approximately one hour. To ensure the accuracy of your input, your permission is asked to audio record the interview.

Participation in the study is entirely voluntary and there are no known or anticipated risks to participation in this study. Your treatment will not be influenced if you agree to be interviewed or decline to be interviewed. If you choose to be interviewed, you may decline to answer any of the questions you do not wish to answer. Further, you may decide to withdraw from this study at any time, without any negative consequences, simply by letting me know your decision. All information you provide will be considered confidential unless otherwise agreed to, and the data collected will be kept in a secure location and confidentially disposed of in five years time.

If you agree to participate kindly indicate your interest by either:

- Contacting Dr. Andrea Covelli at 416-886-6810, or [andrea.covelli@utoronto.ca](mailto:andrea.covelli@utoronto.ca), or by returning the included form in the postage-paid return envelop
- or
- Advise the researcher at the time of the follow up phone call (which will be in approximately 2 weeks after receiving this letter).

If at any time, you have any questions about this study, you can contact either Dr. Andrea Covelli at 416-886-6810 or [andrea.covelli@utoronto.ca](mailto:andrea.covelli@utoronto.ca), or Dr. Baxter at 416- 864-5168.

If you have any questions about your rights as research participant, you can contact Dr. Bob Hyland, Chair of the St. Michael's Hospital Research Ethics Board at 416-864-6060 ext 2557.

Sincerely,  
 Dr. Andrea Covelli, MD PhD (c)  
 Student-Investigator  
 Health Policy, Mgmt. And Evaluation  
 University of Toronto  
[andrea.covelli@utoronto.ca](mailto:andrea.covelli@utoronto.ca)  
 416-886-6810

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Dr. Frances Wright MD, Med, FRCSC  
 Principal Investigator  
 Assistant Professor, University of Toronto  
 Sunnybrook Health Sciences Centre,  
 Division of Surgical Oncology  
 2075 Bayview Ave., Room T2 057,  
 Toronto, ON, M4N 3M5  
 416-480-4210

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Dr. Nancy Baxter MD, PhD, FRCSC, FACRS  
 Co-Investigator  
 Assistant Professor, University of Toronto  
 St. Michael's Hospital,  
 Division of General Surgery  
 30 Bond St. 16CC-040,  
 Toronto, ON, M5B 2H9  
 416-864-516

## Appendix B: Response Form – Patient and Ontario Participants

PLEASE COMPLETE THIS FORM AND MAIL TO THE RESEARCH COORDINATOR IN THE RETURN ENVELOPE PROVIDED. THANK YOU

- ☐ I am interested in participating in this study. I consent to being contacted by the researcher to provide me with additional information and/or to schedule an interview.

I prefer to be contacted during the:

- ☐ Day, please specify a convenient time: \_\_\_\_\_
- ☐ Evening, please specify a convenient time: \_\_\_\_\_
- ☐ Anytime
- ☐ Other, please specify: \_\_\_\_\_

I prefer to be contacted at the following number: \_\_\_\_\_

- ☐ I am not interested in participating in this study. Please do not contact me.

Name: \_\_\_\_\_

Signature: \_\_\_\_\_



## Appendix C: Consent Form – Patient Participants

### Principal Investigator:

Dr. Frances Wright  
Assistant Professor, University of Toronto  
Sunnybrook Health Sciences Centre, Division of Surgical Oncology  
2075 Bayview Ave., Room T2 016 Toronto, ON M4N 3M5  
416-480-4329

### Co-Investigators

Dr. Nancy Baxter MD, PhD, FRCSC, FACRS  
Assistant Professor, University of Toronto  
St. Michael's Hospital, Division of General  
Surgery 30 Bond St. 16CC-040,  
Toronto, ON M5B 2H9 416-864-5168

Dr. Andrea Covelli. MD. Ph (c)  
Dept of Health Policy, Management and Eval  
University of Toronto  
416-886-6810  
andrea.covelli@utoronto.ca

**This study is funded by:** Canadian Breast Cancer Foundation

This is a Master's student study conducted by Dr. Andrea Covelli under the supervision of Dr. Nancy Baxter, (staff physician) at St. Michael's.

### Introduction

*You are being asked to consider taking part in a research study.* Before agreeing to take part in this study, it is important that you read the information in this research consent form. It includes details we think you need to know in order to decide if you wish to take part in the study. If you have any questions, ask a study investigator or study staff. You should not sign this form until you are sure you understand the information. All research is voluntary. You may also wish to discuss the study with a family member or close friend.

### Background/Purpose of the Research

You are being asked to consider participating in this study because you have recently undergone either a unilateral mastectomy (entire removal of the affected breast) or a contralateral prophylactic mastectomy (removal of the opposite, unaffected breast) for the treatment of your early-stage breast cancer.

The purpose of this study is to understand why women are now choosing more extensive surgeries for their treatment of breast cancer; what factors are important when women are making surgical decision's for the treatment of early-stage breast cancer.

In order to understand factors influencing surgical decision making we will conduct one-on-one interviews with women with early breast cancer who underwent surgery within the past 2 years. The intent is to explore the women's experience with regards to her decision-making process. We will then examine the interviews for repeating ideas and themes. From this we hope to develop a theory that helps us understand our question from the woman's experience.

### Description of Research

If you agree and consent to participate in this study, you will be asked to participate in a one on one interview. You will be asked to questions about your surgical treatment for breast cancer, and more specifically your experience in making treatment decisions. . The interview session will be at a convenient time and place and should last approximately 1 hour. The one-on-one will be audio taped and transcribed. If you do not give permission for audio-taping you will not be allowed to participate in the study.

**Potential Harms (Injury, Discomforts or Inconvenience):**

There are no medical risks to you from participating in this study but taking part in this study may make you feel uncomfortable. You may decline to answer questions or stop the interview at any time if you experience any discomfort. Although most participants describe the interview process as a therapeutic tool for discussing their previous treatment there remains the potential that you may experience some discomfort. We can provide support through both a group as well as individual counselling should you request it.

**Potential Benefits:**

This study will not benefit you directly. However the results of the study may help make it possible to improve the overall quality of care for future patients diagnosed with early-stage breast cancer.

**Confidentiality and Privacy:**

The Research Team is committed to respecting your privacy. They will make every effort to keep your study information private and confidential in accordance with all applicable privacy legislation. No information that reveals your identity will be published without consent unless required by law.

You are strongly encouraged to not reveal any information that could identify yourself. Should you reveal any identifiable information during the discussion, this information will not be transcribed, but rather paraphrased to capture the idea/thought expressed. Any names mentioned in the recordings will **not** be transcribed.

All audio files of recorded interviews and other study data (e.g. interview transcripts, completed questionnaires, limited medical information etc.) will be securely stored at Sunnybrook Health Sciences Centre, the primary research site for this study. This information is accessible only to members of the research team and the St. Michael's Research Ethics Board, who may look at study records (such as the consent form), for the purpose of monitoring the study.

Your interview will be audio taped, the tape will be destroyed once it has been transcribed (typed out word for word), verified, and the data has been analysed. The study data (which includes electronic and hard copies of the transcripts or interview notes) will be securely stored for 5 years at Sunnybrook Health Sciences Centre. After the 5 year period the data will be destroyed.

The results of the research will include information from many people grouped together so that no one person can be identified. The only personal information we will have is your name and this will not be reported or shared with anyone outside the research team without your consent or unless required by law.

It is important to understand that despite the confidentiality and privacy protections being in place, there continues to be the risk of unintentional release of information. The study personnel will protect your consent form, the audio-tape and transcripts to the greatest extent possible. The chance that your study information would be accidentally released to unauthorized persons is small.

**Publication of Results:**

Once the study is completed we anticipate publishing the results in a peer-reviewed journal. You will be contacted by mail to be informed of the study results once available.

Although we do not anticipate any restrictions to publication of this study, however if there are restrictions which prevent publication you will be notified.

**Costs of Participation & Reimbursement:**

Taking part in this study may result in added costs to you (such as travel expenses). You will be given \$20 to cover for any study related expenses (such as parking or transportation costs) you may incur.

**Participation and Withdrawal:**

Participation in any research study is voluntary. If you choose not to participate, you and your family will continue to have access to customary care at St. Michael's. If you decide to participate in this study you can change your mind without giving a reason, and you may withdraw from the study at any time without any effect on the care you and your family will receive at St. Michael's.

**Research Ethics Board Contact:**

If you have any questions as a research participant you may contact Dr. Bob Hyland, Chair of the St. Michael's Research Ethics Board at 416-864-6060, extension 2557.

**Study Contacts:**

If you have any questions about the study, please contact: Dr. Andrea Covelli Master's candidate, University of Toronto 416-886-6810, [andrea.covelli@utoronto.ca](mailto:andrea.covelli@utoronto.ca).

**Consent:**

The research study has been explained to me, and my questions have been answered to my satisfaction. I have been informed of the alternatives to participation in this study. I have the right not to participate and the right to withdraw without affecting the quality of medical care at St. Michael's Hospital for me and for other members of my family. As well, the potential harms and benefits (if any) of participating in this research study have been explained to me.

I have been told that I have not waived my legal rights nor released the investigators, sponsors, or involved institutions from their legal and professional responsibilities. I know that I may ask now, or in the future, any questions I have about the study. I have been told that records relating to me and my care will be kept confidential and that no information will be disclosed without my permission unless required by law. I have been given sufficient time to read the above information.

**I consent to participate. I have been told I will be given a signed copy of this consent form.**

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 Name of Participant (Print)

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 Signature of Participant

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 Date

*I have explained the study to the above participant explained the nature and purpose, the potential benefits, and possible risks associated with participation in this research study. I have answered all questions that have been raised.*

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 Name & Position of Person

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 Signature of Person

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 Date

Obtaining Consent (Print)

Obtaining Consent

## Appendix D: Interview Guide – Patient Interviews

*Thank you for participating in this study. This interview will last about 1 hour. I will be asking you several questions about how you and your physician decided what surgery you should have. This conversation is being **recorded**, but your responses will remain **confidential**. At no time during this interview will I refer to you by your name, and should it be stated by yourself we will subsequently delete it from the audio-recording. I ask that you please refrain from using your last name if possible. Some of your responses may be used as quotes when the study is completed, however these quotes will not be linked to your name or any features that would identify you.*

*Before we begin do you have any questions?*

Concept	Questions
Patient Factors Age: Ethnicity: Highest Education: Family History:	
Meaning of Breast Cancer	<ul style="list-style-type: none"> <li>• Would you please describe what breast cancer meant to you before your diagnosis</li> <li>• Would you please describe the events leading up to your diagnosis</li> <li>• Would you please describe the moment you received your diagnosis and what that was like for you</li> <li>• Would you please describe your experiences from the time you received your diagnosis until your surgery</li> </ul>
Experiences with Surgical-Decision Making	<ul style="list-style-type: none"> <li>• How would you <u>describe your surgical experience</u> with your breast cancer treatment?</li> <li>• (prompt): Would you please further expand on your decision making from the time you were diagnosed until surgery?</li> </ul>

	<ul style="list-style-type: none"> <li>• (prompt): What were the important things that you considered when you were making this decision</li> <li>• (prompt): What were the important things that you considered when you were making this decision</li> <li>• (prompt): Was there one thing that had the biggest impact on your decision?</li> <li>• (prompt): Would you please describe what you think your largest concern was when making this decision</li> </ul>
Treatment Factors	<p>Adjuvant Treatment</p> <ul style="list-style-type: none"> <li>• Did you feel that there other treatments to that you chose?</li> <li>• Would you please describe your thoughts and experiences with adjuvant (chemotherapy and radiation therapy).</li> <li>• (prompt): Was adjuvant treatment discussed with you?</li> </ul> <p>Reconstruction</p> <ul style="list-style-type: none"> <li>• What is your understanding of surgical reconstruction? (prompt): Was this discussed with you?</li> </ul>
Surgeon Factors	<p>Information</p> <ul style="list-style-type: none"> <li>• Would you please share those discussions you had with your surgeon (and other members of the health-care team)</li> <li>• What was your understanding of your treatment options discussed with you</li> <li>• (prompt) Did you feel like you understood all options</li> <li>• (prompt) Where there other medical personnel that provided information (if so – describe)</li> </ul> <p>Preference</p> <ul style="list-style-type: none"> <li>• Did you feel like your surgeon preferred one surgery over the other ( why, describe)</li> <li>• (prompt) Did you seek a second opinion?</li> </ul>
External Factors	<p>Information</p> <ul style="list-style-type: none"> <li>• Would you please describe where your information about</li> </ul>

	<p>breast cancer/ breast cancer treatments came from?</p> <ul style="list-style-type: none"> <li>• Would you please describe any information that stands out in your mind (both positive and negative) during your journey with breast cancer</li> <li>• (prompt) – Were there sources of information that were most/ least helpful for you?</li> </ul> <p>Media</p> <ul style="list-style-type: none"> <li>• (prompt) Would you please describe your experience with the media around your breast cancer diagnosis?</li> <li>• (prompt) Was there anything from the media that stood out particularly to you?</li> </ul> <p>Support Groups</p> <ul style="list-style-type: none"> <li>• (prompt) Would you please describe your experience with breast cancer support groups.</li> <li>• (prompt) Was there anything about the support groups that stood out particularly to you?</li> </ul>
Patient Factors	<p>Risk Perception</p> <ul style="list-style-type: none"> <li>• What was the most important to you (largest concern) when you were making your decision</li> <li>• What did you think your risk of dying and /or getting a second cancer was?</li> </ul> <p>Body Image</p> <ul style="list-style-type: none"> <li>• Did you have any concerns about appearance after your treatment?</li> </ul> <p>Lived Experience</p> <ul style="list-style-type: none"> <li>• Would you please describe what has been your previous experience with breast cancer (family/ friends etc)</li> </ul> <p>Support System</p> <ul style="list-style-type: none"> <li>• Would you please describe who your supports were during your breast cancer journey and decision-making?</li> </ul>

	<ul style="list-style-type: none"> <li>• Would you please describe anything or anyone else that might have been influential in the information you received around your breast cancer?</li> <li>• (prompt) -What extent of a role did they play in the decision-making</li> </ul>
Decision-Making Style	<p>Deliberation</p> <ul style="list-style-type: none"> <li>• How much time did you have to discuss the issues that were important to you about your breast cancer?</li> </ul> <p>Decision</p> <ul style="list-style-type: none"> <li>• How involved were you in deciding what treatment you would receive (prompt: physician only/shared)</li> </ul> <p>Role</p> <ul style="list-style-type: none"> <li>• Were you involved in decision-making to the extent you wanted to be?</li> </ul>
	<p>Are there any other factors that were important to you in your journey from your diagnosis to decision-making that we did not discuss?</p> <p>Knowing what you know now is there anything you would have like to have happened differently during your decision-making experience?</p> <p>Is there anything else you want to share?</p>

*Do you have any questions for me?*

*Thank you for taking the time to speak with me.*



## Appendix E: Letter of Invitation to the Study – Ontario Surgeon Participants

Dear Potential Participant:

This letter is an invitation to participate in a research study **Choosing Mastectomy: an exploratory study to understand why women with early-stage breast cancer are choosing to have a mastectomy rather than a breast conserving procedure**

As a full time PhD student in the Department of Health Policy Management and Evaluation at the University of Toronto, Dr. Andrea Covelli is currently conducting research under the supervision of Dr. Baxter and Dr. Wright on surgical decision making in women with early stage breast cancer. This study is being conducted at Sunnybrook Health Sciences Centre.

### Study Overview

Since 2003 patterns of breast cancer surgery have been changing. There has been an increase in the number of women choosing to have mastectomy, and contralateral prophylactic mastectomy, for the treatment of average risk, early-stage breast cancer. We wish to understand and explore why women are choosing the surgeries they do. We want to understand which factors are important and influence women's preference for surgery

As a surgeon who has had first-hand experience, with the decision making process for the breast cancer treatment your perspective may provide key information. I would like to invite you to participate in a telephone interview.

### Your Involvement

A. Covelli will follow up with you by phone to review the goals and method of the study and would be happy to address any other question or concerns you may have. She will arrange a telephone interview at a time convenient to your schedule, and will last approximately 30-45 minutes. To ensure the accuracy of your input, your permission is asked to audio record the interview.

Participation in interview is entirely voluntary and there are no known or anticipated risks to participation in this study. If you choose to be interviewed, you may decline to answer any of the questions you do not wish to answer. Further, you may decide to withdraw from this study at any time, without any negative consequences, simply by letting me know your decision. All information you provide will be considered confidential, and the data collected will be kept in a secure location and confidentially disposed of in five years time.

### Contact Information

If you have any questions regarding this study, or would like additional information about participation, please contact A Covelli PhD(c) at 416-886-6810 or by email

andrea.covelli@utoronto.ca. You can also contact her supervisor Dr. Wright by telephone at 416-480-4210.

This study has been reviewed and cleared by the Sunnybrook Research Ethics Board. However, the final decision to participate is yours. If you have any comments or concerns resulting from your participation in this study, please contact Dr. F. Wright at 416-480-4210. Thank you in advance for your interest and assistance with this research.

If you agree to participate kindly complete the form attached to this letter to indicate your interest in participating in this research study and mail back in the envelope provided.

Yours very truly,

Dr. Frances Wright MD, M.Ed, FRCSC  
Sunnybrook Health Sciences Centre,  
Division of Surgical Oncology  
2075 Bayview Ave., Room T2 057,  
Toronto, ON, M4N 3M5  
416-480-4210

## Appendix F: Consent Form – Surgeon Participants

**TITLE:** Choosing Mastectomy: A Qualitative Exploration of the Increasing Mastectomy Rates in Women with Early-Stage Breast Cancer

**INVESTIGATOR:** Dr. Frances Wright MD, MEd, FRCSC

Sunnybrook Health Sciences Centre,  
Division of Surgical Oncology  
2075 Bayview Ave., Room T2 016,  
Toronto, ON, M4N 3M5  
416-480-4329

**SPONSOR:** Canadian Breast Cancer Foundation

This study is part of a PhD dissertation conducted by Dr. Andrea Covelli under the supervision of Dr. Frances Wright, (staff physician) at Sunnybrook Health Sciences Centre.

You are being asked to consider participating in a research study. A research study is a way of gathering information on a treatment, procedure or medical device or to answer a question about something that is not well understood.

This form explains the purpose of this research study, provides information about the study procedures, possible risks and benefits, and the rights of participants.

Please read this form carefully and ask any questions you may have. You may take as much time as you wish to decide whether or not to participate. Please ask the study staff or one of the investigator(s) to clarify anything you do not understand or would like to know more about. Make sure all your questions are answered to your satisfaction before deciding whether to participate in this research study.

### INTRODUCTION

You are being asked to consider participating in this study because you currently perform surgical treatment for early-stage breast cancer including; unilateral mastectomy and contralateral prophylactic mastectomy.

#### Background:

Since 2003 patterns of breast cancer surgery have been changing. There has been an increase in the number of women choosing to have either unilateral mastectomy or contralateral prophylactic mastectomy, for treatment of their early-stage breast cancer.

Some studies have attributed this change to women playing a more active role in their surgical decision making, however these studies do not describe the factors women are considering in their decision making process. Through our study we wish to understand why women with early breast cancer are choosing the surgeries they do. We wish to understand which factors are important and influence women's preference for surgery.

We are hoping to understand what exactly matters to women when making such a decision and understanding what your experience with patients has been is fundamental to our study. By better understanding the decision making process we can improve our ability as health care professionals to discuss issues of importance to women, and assist in their decision making.

As a surgeon who provides treatment for women with breast cancer, your understanding and perspective of the decision-making process which women undergo, can provide key information. I would like to invite you to participate in a telephone interview.

### **WHY IS THIS STUDY BEING DONE?**

The purpose of this study is to understand why women are now choosing more extensive surgeries for their treatment of breast cancer; what factors are important when women are making surgical decision's for the treatment of early-stage breast cancer.

In order to understand factors influencing surgical decision making we are conducting one-on-one interviews with women with early breast cancer who have recently undergone surgery. It is known that a treatment preference held by the surgeon is often perceived by the patient, even when the surgeon holds no true preference; women who described themselves as active decision-makers; more often undergo UM and perceive this as the surgeon's preference. To more fully understand this phenomenon in the context of changing surgical trends we wish to gain your perspective on surgical decision-making.

### **WHAT WILL HAPPEN DURING THIS STUDY?**

Your participation in this study involves a 30-45 minute interview with the researcher. The interviews will take place over the telephone at a time which is convenient for you. During the interview, you will be asked several open-ended questions that instruct you to reflect on your experience with patients during their surgical decision-making process. There are no right or wrong answers to the questions, you will be asked for your opinions only. The conversation will be recorded but your responses will remain completely confidential.

### **HOW MANY PEOPLE WILL TAKE PART IN THE STUDY?**

It is anticipated that about 20 surgeons will participate in this study from centres across Ontario. The entire study is expected to take about 1 year to complete and the results should be known in 1.5 years.

### **WHAT ARE THE RESPONSIBILITIES OF STUDY PARTICIPANTS?**

If you decide to participate in this study you will be asked to do the following: Participate in one semi-structured interview lasting approximately 30-45 minutes.

### **WHAT ARE THE RISKS OR HARMS OF PARTICIPATING IN THIS STUDY?**

We do not anticipate any harm or arising from participation in this study. However, if personal identifying information was inappropriately released then there is the potential for loss of anonymity. In addition you may decline to answer any of the interview questions or stop the interview at any time.

### **WHAT ARE THE BENEFITS OF PARTICIPATING IN THIS STUDY?**

**There are no direct benefits from participating in this study.** Your feedback may help make it possible to improve the overall quality of care for future patients diagnosed with early-stage breast cancer.

### **CAN PARTICIPATION IN THIS STUDY END EARLY?**

The investigator may decide to remove you from this study without your consent for any of the following reasons.

- You are unable or unwilling to follow the study procedures.

If you are removed from this study, the investigator will discuss the reasons with you. You can also choose to end your participation at any time. If you withdraw voluntarily from the study you are encouraged to contact Dr. Andrea Covelli, PhD candidate University of Toronto, 416-886-6810, [andrea.covelli@utoronto.ca](mailto:andrea.covelli@utoronto.ca) immediately.

### **WHAT ARE THE COSTS OF PARTICIPATING IN THIS STUDY?**

Participation in this study will not involve any additional costs to you.

### **ARE STUDY PARTICIPANTS PAID TO PARTICIPATE IN THIS STUDY?**

You will not be paid to participate in this study however you will receive a small gift certificate to thank you for your time.

### **DO THE INVESTIGATORS HAVE ANY CONFLICTS OF INTEREST?**

There are no conflicts of interest to declare related to this study.

### **WHAT ARE THE RIGHTS OF PARTICIPANTS IN A RESEARCH STUDY?**

All participants in a research study have the following rights:

1. You have the right to have this form and all information concerning this study explained to you and if you wish translated into your preferred language.
2. Participating in this study is your choice (voluntary). You have the right to choose not to participate, or to stop participating in this study at any time without having to provide a reason. Should you choose to withdraw from the study you are encouraged to contact: Dr. Andrea Covelli PhD candidate, University of Toronto 416-886-6810, [andrea.covelli@utoronto.ca](mailto:andrea.covelli@utoronto.ca) immediately.
3. You have the right to receive all significant information that could help you make a decision about participating in this study. You also have the right to ask questions about this study and your rights as a research participant, and to have them answered to your satisfaction, before you make any decision. You also have the right to ask questions and to receive answers throughout this study. If you have any questions about this study you may contact the person in charge of this study (Principal Investigator) Dr. Andrea Covelli PhD candidate, University of Toronto 416-886-6810, [andrea.covelli@utoronto.ca](mailto:andrea.covelli@utoronto.ca) or Dr. Frances Wright Department of Surgery 416-480-4210. If you have questions about your rights as a research participant or any ethical issues related to this study that you wish to discuss with someone not directly involved with the study, you may call Dr. Philip C. Hébert, Chair of the Sunnybrook Research Ethics Board at (416) 480-4276.

4. Any study data about you will have a code and will not contain your name or address, or any information that directly identifies you. "Study data" is information about you that is collected for the research study, but that does not directly identify you.  
The investigator(s), and study staff will keep the information they see or receive about you confidential, to the extent permitted by applicable laws. Even though the risk of identifying you from the study data is very small, it can never be completely eliminated.  
When the results of this study are published, your identity will not be disclosed. The Principal Investigator will keep any personal information about you in a secure and confidential location for 5 years and then destroyed as required by Sunnybrook policy
5. By signing this consent form, you do not give up any of your legal rights.
6. You have the right to receive a copy of this signed and dated informed consent form before participating in this study.
7. You have the right to be told about any new information that might reasonably affect your willingness to continue to participate in this study as soon as the information becomes available to the study staff.
8. You have the right to access, review and request changes to your personal health information.
9. You have the right to be informed of the results of this study once the entire study is complete. If you would like to be informed of the results of this study, please provide your name, address and telephone number to or Dr. Andrea Covelli PhD candidate, University of Toronto 416-886-6810, [andrea.covelli@utoronto.ca](mailto:andrea.covelli@utoronto.ca)
- 10.

### DOCUMENTATION OF INFORMED CONSENT

**Full Study Title: Choosing Mastectomy: A Qualitative Exploration of the Increasing Mastectomy Rates in Women with Early-Stage Breast Cancer**

Name of Participant: \_\_\_\_\_

Participant/Substitute decision-maker

By signing this form, I confirm that:

- This research study has been fully explained to me and all of my questions answered to my satisfaction
- I understand the requirements of participating in this research study
- I have been informed of the risks and benefits, if any, of participating in this research study
- I have been informed of any alternatives to participating in this research study
- I have been informed of the rights of research participants
- I have read each page of this form
- I authorize access to my personal health information, medical record and research study data as explained in this form
- I have agreed to participate in this study or agree to allow the person I am responsible for to participate in this study

_____	_____	_____
Name of participant	Signature	Date

**Person obtaining consent**

By signing this form, I confirm that:

- This study and its purpose has been explained to the participant named above
- All questions asked by the participant have been answered
- I will give a copy of this signed and dated document to the participant

_____	_____	_____
Name of Person Obtaining Consent	Signature	Date

**Statement of Investigator**

I acknowledge my responsibility for the care and well being of the above participant, to respect the rights and wishes of the participant as described in this informed consent document, and to conduct this study according to all applicable laws, regulations and guidelines relating to the ethical and legal conduct of research.

_____	_____	_____
Name of Investigator (print)	Signature	Date

## Appendix G- U.S. Surgeons Email Invitation

Hello Dr. \_\_\_\_\_

I am a general surgery resident at the University of Toronto; in addition, I have entered the research program offered here which temporarily allows me to pursue a graduate degree. I am currently working towards completing my PhD under the supervision of Drs. Nancy Baxter and Frances Wright through the Institute of Health Policy, Management and Evaluation in clinical epidemiology. I been in contact with Dr. \_\_\_\_\_ and he/ she recommended that I contact you to see if you might be interested in participating in an telephone interview which I am conducting as part of my dissertation.

Very briefly, my thesis is around the choice of mastectomy (unilateral or bilateral) for the treatment of stage 1/2 breast cancer in average risk women; this was developed in response to the increasing mastectomy rates being reported over the past few years. As part of my dissertation I conducted qualitative interviews with women who have undergone either a unilateral mastectomy, or bilateral mastectomy for the treatment of early-stage breast cancer. In addition to the patient interviews I am also interested in the surgeon's perspective on these changing surgical trends, as well as their own personal experience with women requesting such surgeries.

I had initially completed interviews with both academic and community surgeons in Ontario. In hopes of complementing the Ontario interviews we then began to interview high volume breast surgeons in the United States. To date we have only completed pilot interviews but it appears that the American surgeon experience may differ from what was reported in Ontario. In attempts to better understand the surgeon's experience we are hoping to interview both academic and community breast surgeons in the United States. Dr. \_\_\_\_\_ suggested I contact you, as your insight and experience would be invaluable.

The interview itself is conducted over the phone at a time of your convenience and would last approximately 35-45 minutes; it is completely anonymous and you are de-identified from your answers. I am happy to discuss the study itself, the interview guide, the interview process or answer any questions you may have. I have attached both the letter of invitation as well as the consent here. I am happy to discuss the study itself, the process of the interview or any questions you may have.

I truly appreciate the consideration. Please let me know if I can provide any further information.

Sincerely,

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PGY3 General Surgery  
Institute of Health Policy, Management and Evaluation  
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## Appendix H: Surgeon Interview Guide

*“Thank you for participating in this study. The interview will last between 45 and 60 minutes. I will be asking you several questions about what your current surgical management is for early-stage breast cancer and your recent experience with patients undergoing more extensive surgical options. I will ask you a few questions about yourself as well as your practice location and training before we begin the interview and these answers will not be recorded. Following these questions I will then begin the interview and the remaining responses will be recorded. All of your responses will remain confidential. Before we begin do you have any questions?”*

Concept	Questions
<u>Surgeon Factors **</u> <i>Age:</i> <i>Length of Surgical Practice:</i> <i>Locations of Surgical Practice (current and previous):</i> <i>Location of Surgical Fellowship (if applicable):</i> <i>Percent caseload devoted to breast cancer surgery:</i>	<p>** these questions responses will only be recorded privately by the interviewer prior to the onset of the interview</p> <p>** these responses will be treated as personally identifying information and stored separate from the study data</p> <p>For the purpose of the study data these response will be numerically coded</p>
General Surgical Approach	<ul style="list-style-type: none"> <li>• Would you please describe your current surgical approach to treatment of early-stage breast cancer</li> <li>• (prompt): Please describe your approach to the first consultation with a newly diagnosed/highly suspicious case of early-stage breast cancer?</li> <li>• (prompt): do you suggest a preferred surgery or do you describe all surgical options</li> </ul>

	<p>available</p> <ul style="list-style-type: none"> <li>• (prompt): please describe instances in which you would strongly recommend one surgical option over another</li> <li>• Please describe any continuing education activities you participate in specific to breast cancer (ex. conferences/journals etc)</li> </ul>
Decision-Making	<ul style="list-style-type: none"> <li>• What is your approach to patients who express a preferred treatment at the onset of first consultation (prompt) – do you discuss all surgical options (prompt) – do you discuss the risks and benefits of each option (prompt) – in your experience to patients alter their decisions, if so when/why</li> <li>• Please describe your approach to a patient who expresses interest in a surgical option that you wouldn't routinely recommend (prompt): Does this differ from a patient who voices the option you would recommend – please describe</li> <li>• What is your impression of what patients consider important when deciding between surgical treatment options ? (prompt): Would you please describe what you think their largest concern is when making this decision?</li> <li>• Please describe any decision-making aids you may use when discussing surgical options with your patients? (prompt): Have you had any experience with decision-making aids- if so, please describe</li> </ul>
Surgeon Preference	<ul style="list-style-type: none"> <li>• Do you think there is an optimal treatment approach for the average-risk women with early-stage breast cancer?</li> <li>• Do you have a personal preference to the surgical treatment you would prefer if it was yourself or a loved one with this diagnosis?</li> </ul>
Treatment Related Factors	<p>Adjuvant Treatment</p> <ul style="list-style-type: none"> <li>• Please describe the discussion you might have with women on adjuvant treatment (prompt): Do you routinely discuss the role of radiation in your surgical discussion? if so; would you please describe how you present this to the patient</li> </ul>

	<p>(prompt): What information do you share about radiation (prompt):Do you mention the major risks and benefits of radiation?</p> <p>Reconstruction</p> <ul style="list-style-type: none"> <li>Do you routinely discuss the role of surgical reconstruction in your surgical discussion? if so; would you please describe how you present this to the patient</li> <li>Is immediate reconstruction available to your patients?</li> </ul> <p>Prosthesis</p> <ul style="list-style-type: none"> <li>Do you routinely discuss the use of prosthesis in your surgical discussion? if so; would you please describe how you present this to the patient</li> </ul> <p>MRI</p> <ul style="list-style-type: none"> <li>Would you please describe your opinion and use of MRI in breast cancer care (prompt): Would you please describe your use of MRI in a patient who is being worked up/ diagnosed for breast cancer (prompt): What do you think is the ideal use of MRI in breast cancer patients</li> <li>Would you please describe your access to MRI</li> </ul>
Risk Perception	<p>Risk Reduction/Survival</p> <ul style="list-style-type: none"> <li>Please describe what information you might share with patients around risks and benefits of treatment options (prompt):Do you routinely discuss the risk of recurrence and survival benefit (prompt): do you routinely use any statistics, graphs or charts</li> <li>What is your impression of the patient's understanding of risk reduction of recurrence vs. mortality as it applies to treatment options?</li> </ul> <p>Priorities</p> <ul style="list-style-type: none"> <li>What is your impression of the patient's treatment priorities in those patients who opt for more extensive surgery</li> </ul>

Surgical Trends	<ul style="list-style-type: none"> <li>• What is your personal experience of the surgical procedures undergone for early-stage breast cancer in average risk women over the past five years? (prompt): Do you feel like there has been a change the amount of surgeries you perform (ie. BCS, UM, CPM)</li> <li>• What is your impression of the changing surgical trends as reported in the literature? (prompt): what do you think are the factors influencing this trend? (prompt): has this trend been presented/discussed with colleagues? (prompt):What is your response to this changing trend?</li> <li>• What is your response to breast cancer surgery as a quality-care indicator?</li> </ul>
Patient Factors	<p>Information</p> <ul style="list-style-type: none"> <li>• In your opinion where did most patients get their information come from</li> <li>• Do you recommend the patient seek other sources of information during their decision making?</li> </ul> <p>Support Groups</p> <ul style="list-style-type: none"> <li>• What role, if any, do you think support groups play (or could potentially play) in women's breast cancer experience</li> <li>• (prompt): Are there any support groups associated with your surgical centre?</li> </ul> <p>Body Image</p> <ul style="list-style-type: none"> <li>• Would you please describe the discussion you have with patients around body image and cosmesis (prompt): Who initiates this conversation? (prompt): Are there any tools or information you provide to patients?</li> </ul> <p>Support System</p> <ul style="list-style-type: none"> <li>• What is your experience of the role that family members and friends play in the decision-making process?</li> </ul>
Patient Involvement	Deliberation

	<ul style="list-style-type: none"> <li>• How much time do patients routinely have to discuss these issues?</li> </ul> <p>Decision</p> <ul style="list-style-type: none"> <li>• How involved do you feel patients are in the decision-making process?</li> <li>• Have you noticed a pattern in decision-making and the surgeries patients have (prompt): Degner's work has described active decision makers (provide definition) as more likely to choose more extensive surgery – please comment on this statement</li> </ul>
Media Factors	<ul style="list-style-type: none"> <li>• Would you describe your impression of the role the media plays in decision-making (prompt) –Are you able to recall any specific examples (prompt: patient encounters prompt: memorable media)</li> <li>• Would you describe what you recall seeing in the media with regards to breast cancer treatment</li> <li>• Have you personally had any experience using the media as a source of information</li> </ul>
	<p>Are there any other factors that impact decision-making that we did not discuss?</p> <p>Is there anything else you want to share?</p>

*Thank you very much for taking the time to share with me.*