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## “I don’t want to take chances.”: A qualitative exploration of surgical decision making in young breast cancer survivors

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### Abstract

**Objective:** Young women with unilateral breast cancer are increasingly choosing contralateral prophylactic mastectomy (CPM), despite its limited medical benefit for most women. The purpose of this study was to better understand this choice through a qualitative exploration of surgical decision-making in young survivors, including how issues particular to younger women affected their decision and the post-surgical experience.

**Methods:** Women age 40 years with stage 0-III breast cancer, 1-3 years from diagnosis who had undergone breast cancer surgery were recruited to participate. Four focus groups were conducted: two with women who had bilateral mastectomy and two with women who kept their contralateral breast. Focus groups were recorded and transcribed with identifiers removed. Emergent themes were identified by thematic content analysis using NVivo 11.

**Results:** Of the twenty participants, median age at diagnosis was 37 years. Emergent themes were categorized into the following domains 1) emotions/feelings surrounding surgery/decision about surgery; 2) factors affecting the decision; 3) communication and interaction with the healthcare team; 4) impact on post-surgical life and recovery; 5) support needs. Young women who chose CPM often were concerned about a future breast event, despite this low risk, suggesting some gain peace of mind by choosing CPM. Young survivors also had many physical and emotional concerns after surgery for which they did not always feel prepared.

**Conclusions:** Informational resources and decision aids may enhance patient-doctor communication and help young survivors better understand risk and manage expectations surrounding short and longer-term physical and emotional effects after surgery.

### Keywords

breast cancer; oncology; surgery; decision-making; contralateral prophylactic mastectomy

### Introduction

Increasing numbers of women with early-stage unilateral breast cancer in the United States are choosing to have their unaffected breast removed, a procedure known as contralateral prophylactic mastectomy (CPM).<sup>1–3</sup> This trend has been particularly evident in the youngest

women with breast cancer. In recent studies, the reported prevalence of CPM among young women (defined as age 20-44<sup>4</sup> in one study and younger than 40 in another<sup>2</sup>) ranges from 33% to approximately 43% in a study of women diagnosed at age 40 and younger.<sup>5</sup> While CPM reduces the risk of developing a contralateral breast cancer, for most women (e.g., those without a BRCA1 or BRCA2 mutation) this risk is relatively low, with the 5-year risk estimated to be <5%. Furthermore, there is no evidence that CPM improves survival,<sup>2, 3</sup> thus this procedure is of limited medical benefit for most women.

The socio-demographic, clinical, and psychological contributors to CPM have been well established<sup>6-8</sup> and prior research has also highlighted the relationship between patient-driven decision making and CPM.<sup>9-11</sup> As breast cancer treatment can profoundly impact quality of life, understanding how and why young women make certain decisions about surgery, including undergoing CPM, can have important implications. Young breast cancer survivors often contend with unique issues due to their life stage, including fertility, breastfeeding, and caring for young children, when making these choices. Importantly, many issues of concern to younger women have the potential to affect both short and long-term survivorship and should be addressed early in the treatment trajectory, especially given that younger women are more likely to experience negative psychosocial outcomes than older women following their diagnosis.<sup>12</sup> Using a series of focus groups, we sought to gain an in-depth understanding of the surgical decision-making process and post-surgical experience of young women diagnosed with breast cancer at age 40 and younger.

## Methods

### Recruitment

We emailed information about this qualitative study to women who are part of the Dana-Farber Cancer Institute's (DFCI) "Young and Strong: The Program for Young Women with Breast Cancer", a clinical program that shares educational and resource information designed for young women with breast cancer.<sup>13</sup> Women also were recruited through email invitations sent to participants of an ongoing prospective cohort study, The Young Women's Breast Cancer Study, based at DFCI who had agreed to be contacted for additional research opportunities. Eligibility criteria for the current study included: 1) having a diagnosis of Stage 0-III breast cancer at age 40 and younger; 2) being between one and three years from diagnosis at the time of recruitment; 3) having had either a bilateral mastectomy, unilateral mastectomy, or lumpectomy; 3) having no evidence of recurrent or metastatic disease; and 4) being between 18-43 years of age at the time of recruitment.

### Procedures

A total of four focus groups were held at DFCI between February 2016 and June 2016. Two focus groups included only women who had bilateral mastectomies and two included women who had kept their contralateral breast (i.e., had a lumpectomy or unilateral mastectomy). A semi-structured format focus group guide was developed with diverse stakeholder input, including clinicians, researchers, and breast cancer survivors who reviewed and provided feedback about the content and topic areas. The guide, designed to explore the decision-making process and post-surgical experience, covered the following

areas: 1) decisional conflict/choices/options; 2) personal preferences; 3) genetic testing; 4) surgical outcomes and expectations; 5) information; 6) anxiety/support; and 7) communication.

After providing signed informed consent, participants completed a brief survey that assessed socio-demographic, clinical, , and decision-making information.. Participants received a \$40 gift card in appreciation of their time. This research study was approved by the DFCI Institutional Review Board.

## Analysis

All focus group sessions were audio recorded and transcribed with identifiers removed. Following an initial review of two of the four transcripts and the creation of a preliminary codebook, transcripts were independently coded by two researchers (SMR and MLG) using NVivo software v11 (QSR International, Burlington, MA). Analysis was conducted using thematic content analysis, and the analytic phases included becoming familiar with the data, generating initial codes, coding transcripts, searching for and reviewing themes and patterns, and defining and naming themes.<sup>14, 15</sup> Coded transcripts were compared and discrepancies were discussed between the coders and resolved by consensus. Additional codes not originally included in the codebook were added as needed during the coding process. Survey data was analyzed using SAS v9.4 (SAS Institute, Cary, N.C.). Descriptive statistics, including means, medians, and frequency distributions were used to characterize study participants.

## Results

### Participant characteristics

Of 75 women who responded with interest in the study, 52 met study eligibility criteria. Of these, twenty women participated in the four focus group discussions (four to six women per focus group). Participants' median age at diagnosis was 37 years (range: 29-40 years) and 70% (n=14) of women had either Stage I (n=4) or II (n=10) disease at diagnosis. Most participants (18/20, 90%) identified as White non-Hispanic. Among the women who kept their contralateral breast, most had a lumpectomy (7/9, 78%). Few women (4/20, 20%) were carriers of a breast cancer pre-disposing mutation (e.g., BRCA1, BRCA2, or p53).

### Emergent domains and themes

Identified themes were categorized into five primary domains with several themes corresponding to each domain:

#### **Domain 1: Emotions and feelings surrounding the surgical decision and surgery (Table 1):**

**Theme 1: Confidence with the surgical decision:** Upon reflection, most women felt sure they had made the right decision. Irrespective of the surgery they ultimately had, women voiced satisfaction with their choice.

**Theme 2: Feelings of uncertainty and regret:** Even though, in retrospect, women were confident they had made the surgical decision that was right for them, some women voiced feelings of uncertainty about their decision. Women reflected on the uncertainty they felt when they were considering their options as well as in questioning some aspect of their decision after the fact.

**Theme 3: “I needed it out”:** Some women articulated how difficult it was to know the cancer was physically present in their bodies. They expressed wanting to have the cancer removed as soon as possible.

## **Domain 2: Factors affecting surgical decisions (Table 2)**

**Theme 1: Choosing bilateral mastectomy to provide peace of mind:** Concern about contralateral breast cancer and recurrence were common among women who chose bilateral mastectomy. For some women, the need for continued surveillance had they chosen to keep both of their breasts affected their decision.” In contrast, one participant who had a lumpectomy acknowledged that choosing less extensive surgery upfront left her with the choice to have bilateral mastectomy in the future should she recur.

**Theme 2: Concerns about cosmesis and self-image:** Cosmetic symmetry was cited by several women as a reason for choosing bilateral mastectomy. One woman said her choice of unilateral mastectomy was based on her perception that a “lumpectomy wouldn’t have aesthetically looked as good.” Another participant described that her realization that her breasts were an integral component of her body was her motivation for insisting she have a lumpectomy, despite her doctors’ recommendation to undergo a unilateral mastectomy.

**Theme 3: Pregnancy and breastfeeding are factors in the decision-making process:** A woman who was pregnant at the time of diagnosis spoke of how her pregnancy “threw a little wrench” in her consideration of her surgical options; ultimately, she decided to have a unilateral mastectomy. A participant who chose lumpectomy cited her desire to be able to breastfeed if she had children later as a factor in her decision.

**Theme 4: The influence of genetic testing on the surgical decision:** Some women spoke of the results of genetic testing conducted prior to surgery affecting their surgical decision making, with a negative result reinforcing a decision not to undergo bilateral mastectomy. Some women who had CPM and tested negative said that knowing these results did not affect their decision while others who tested positive for a cancer pre-disposing mutation cited this as a reason for their choice.

**Theme 5: Varied sources of information and recommendations were utilized:** Participants described a range of resources sought and used during the decision process. Doctors and other providers were frequently mentioned as being sources of information about surgery, including directing patients to specific resources (e.g., books, websites) and drawing pictures or showing photos to help women see what their breasts might look like after surgery. Women also spoke of how family, friends, colleagues, and breast cancer survivors, were sources of information.. Women commented on both quality

(e.g., consistency, clarity, and adequacy) as well as timing of the information they sought and received. For some women, regardless of surgery, learning about their surgical options, including reconstruction, often felt overwhelming.

**Theme 6: Second opinions and having time to consider options were valued:** Some women valued having time to consider their treatment options.. For example, one participant who was breastfeeding at the time of diagnosis spoke of how receipt of neo-adjuvant chemotherapy allowed her time to think about her surgical choices. Most women considered second opinions from other doctors to be a valuable part of the decision process.

### **Domain 3: Communication and interaction with the healthcare team (Table 3):**

**Theme 1: Communication of surgery-related information and post-surgical expectations:** Overall, most participants articulated that they generally received sufficient information from their providers about what recovery would be like and that this information was clearly communicated. Nonetheless, while in many cases women were aware of the potential challenges they might encounter after surgery, there was a sense that they had underestimated what these challenges would be like. Other women felt the information provided to them was inadequate and that they were not well prepared for what to expect after surgery.

**Theme 2: Quality of interaction with the healthcare team:** Participants reflected both positively and negatively on the interactions they had with their providers. Many expressed trust in their team's recommendations and appreciated the effective and helpful communication of information. Negative experiences included a lack of communication and feeling, and in some instances, feeling pressured by doctors to choose a particular surgical option.

### **Domain 4: Impact on post-surgical life and recovery (Table 4)**

**Theme 1: Experiencing physical sequelae:** Across all surgery types, women experienced a range of physical challenges following surgery which, in many cases, were unexpected. Participants focused on three specific physical after-effects of surgery: 1) drains, 2) pain, and 3) numbness. A few women spoke of physical limitations that resulted from surgery that impacted their ability to care for their young children.

**Theme 2: Adjusting to a new normal:** Many women reflected on the duration and intensity of surgery's impact on their emotional well-being. Across all surgery types, women spoke about how many aspects of their life had changed as a consequence of their surgery, including sexuality, intimacy, and image. While women were accepting of this "new normal" that followed their diagnosis and surgery, there was also recognition of the difficulty of adjusting to changes in both body and self-image.

**Theme 3: Adapting to post-surgical challenges:** Some women identified helpful strategies to deal with post-surgical challenges, such as wearing special tank tops and doing certain exercises. Women cited the importance of routine and normalcy, including returning to work, as providing motivation for getting through this trying period. While many women

were successful at coping with physical and emotional changes, some remarked that certain resources would have been helpful to know about beforehand to help feel better prepared to manage these changes. Specifically, some women commented that physical therapy was not discussed or was a struggle to obtain, or that the amount of rehabilitation they received was inadequate.

#### **Domain 5: Young women with early breast cancer had different support needs (Table 4)**

**Theme 1: Support received before and after surgery was adequate and helpful for most women:** The majority of women appreciated and found helpful a range of both emotional and material support from partners, family, friends, colleagues, and other breast cancer survivors. .. Examples of offered support included work colleagues being empathetic when one woman experienced “slow days,” a significant other helping with post-operative drains, and parents moving in for an extended period to help at home and with children.

**Theme 2: Support was described as inadequate or not wanted by some women:** Some women spoke of having difficulty finding adequate peer support resources or support groups when they needed it, and sometimes attributed this to their being diagnosed at a younger age than most women with breast cancer. One participant noted a sense of abandonment from friends who “didn’t want to be a part of” her experience. Importantly, not all women wanted or needed external or peer support, particularly when they were newly diagnosed.

**Theme 3: Willingness to serve as a resource to others:** Several women spoke of how, after their own diagnosis and treatment, they wanted to help others by sharing their own experiences with those recently diagnosed.

## **Discussion**

Surgical decisions can be overwhelming and emotionally complex for young women with early-stage breast cancer with factors specific to their early life stage particularly affecting decision-making and their post-surgical experience. Several themes that emerged in this study reflected this complexity, particularly the tension between some of the emotions which were commonly expressed by women regarding their treatment. Consistent with other studies that have examined satisfaction with surgical decisions,<sup>11, 16–20</sup> most women in our study voiced confidence and satisfaction with their surgical choice. However, despite this confidence, some women said that, at times, they felt uncertain in some way about their decision. In a study of young women, Fernandes-Taylor and Bloom (2011) reported that over 40% of young women surveyed 5 years after their breast cancer diagnosis indicated some treatment-related regret, with nearly one-quarter of these women attributing this regret to their surgical treatment.<sup>21</sup>

As more younger women undergo CPM,<sup>2, 4</sup> understanding why they choose this procedure despite the lack of evidence of medical benefit for most women is critical. Prior work by our group examining young women’s reasons for choosing CPM revealed that “peace of mind,” improved survival, and reduced risk of contralateral breast cancer are among the most important reasons given.<sup>18</sup> Similarly, others also have reported on the relationship between

peace of mind and CPM<sup>22, 23</sup> as well as higher levels of concern about recurrence or cancer worry and CPM<sup>24, 25</sup> in breast cancer patients. Findings from our study confirm the influence of concern about future breast cancer events and choosing CPM and highlight the challenge of communicating breast-cancer specific risks, particularly among the youngest women with breast cancer. Specifically, breast cancer in women younger than 40 is relatively rare; thus, some young women may have difficulty believing that risk estimates apply to them, and even a small level of risk may not be acceptable, and therefore choose more extensive surgery.

Due to their life stage, young women may have different priorities when considering their surgical options than older women. Concerns about how surgery would affect appearance and image were influential in the decision process among many participants in our study, which aligns with findings from other studies that have found image to be a significant consideration particularly for younger women making decisions about breast cancer treatment.<sup>26, 27</sup> Other themes across domains emerged as salient to young women, including the ability to breastfeed in the future and the impact of an extended recovery after reconstruction on the ability to care for young children. The relevance of these issues to younger women underscores a need for providers to bring up these topics with their young patients in particular when they are discussing surgical options. Informational resources and decision aids should be tailored to young women to make them optimally relevant and useful.

Knowledge about what comes after surgery can be useful to women during the decision process and our findings suggest that many young survivors have physical and emotional challenges after surgery for which they may not feel prepared. . Body image was a concern irrespective of surgery type and was cited by women when talking about adjusting to a “new normal”, highlighting the need to prepare and support women around image changes that can be difficult to adapt to. In a series of focus group conducted with young breast cancer survivors, Ruddy et al. (2013) similarly found that adjusting to the alterations in physical appearance that were a consequence of treatment, including those attributable to surgery were difficult for young women.<sup>28</sup> While communication of information and expectations surrounding surgery is an essential part of treatment decision making, the role of support is also critical. Reassuringly, while the majority of women in our study felt they had been adequately supported, a few participants expressed a sense of isolation during this time. Efforts to increase the awareness of resources (e.g., Young Survival Coalition<sup>29</sup>) that help support young women regardless of where they live or are treated should be encouraged to help women during all stages of the treatment and survivorship trajectory.

### Study limitations

We acknowledge our study has limitations. Although a range of surgical choices and experiences were represented in our focus groups and participants were treated at various institutions, participants were predominantly, White non-Hispanic and college-educated; thus, the generalizability of study findings might be limited. Women who participated in this study were between one and three years' post-diagnosis, so there is a possibility of recall bias regarding what happened early in their treatment course. However, given that one of the



primary purposes of the current study was to explore both the short and long-term impact of surgery, engaging young women in many phases of their survivorship allowed us to hear how they reflect on both the immediate and non-immediate effects of surgery.

### Clinical implications

Our study highlights the influence and impact of the many physical and emotional factors related to the decision-making process surrounding surgery and post-surgical experience for young women with early breast cancer. Enhancing patient-doctor communication prior to surgery along with ensuring receipt of supportive care and assistance managing their post-surgical needs should help young women in their transition from active surgical treatment to survivorship.

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**Table 1.**

Domain 1: Emotions and feelings surrounding the surgical decision and surgery

Theme	Quote	Surgery type
<b>Confidence with the surgical decision</b>	“Well, I don’t want to take chances,”...just get rid of the other one too...I’m happy I did.	Bilateral mastectomy with reconstruction
	“	
<b>Feelings of uncertainty and regret</b>	“I try not...to second guess it but I think you always can say what if I only had a lumpectomy I wouldn’t have to go through all this.”	Unilateral mastectomy with reconstruction
	“...the only time I ever question myself is the night before my mammogram...and then I’m like...why didn’t I just get the mastectomy...but then...I feel comfortable with the decision.”	Lumpectomy
	“	
<b>“I needed it out”</b>	“... I wanted it out...I couldn’t even think straight until it was out.”	Lumpectomy

**Table 2.**

Domain 2: Factors affecting surgical decisions

Theme	Quote	Surgery
<b>Choosing bilateral mastectomy to provide peace of mind</b>	"I wanted to think that I had tried at least everything...I don't want to live with the regret 'I should have done, you know, double mastectomy'..."	Bilateral mastectomy with reconstruction
<b>Concerns about cosmesis and self-image</b>	"...I care deeply about my breasts," and uh, it's not because of sex... They're part of my body..."	Lumpectomy
	"The biggest concern was symmetry and how natural it could look."	Bilateral mastectomy with reconstruction
<b>Pregnancy and breastfeeding are factors in the decision-making process</b>	"...I thought, 'Well, if I were to ..have a baby...what if I couldn't breast feed?' "	Lumpectomy
<b>The influence of genetic testing on the surgical decision</b>	"...my decision was really based on the genetic testing...if I carried the gene I was ready to do a double mastectomy/ hysterectomy...luckily it came back negative"	Lumpectomy
<b>Varied sources of information and recommendations were utilized</b>	"...I would talk to the other women that, that went through it...I was able to get... details that were going to help my husband take care of me that weren't in any of the doctor's information..."	Bilateral mastectomy with reconstruction
<b>Second opinions and time to consider options were valued</b>	"I think a second opinion is very helpful. That gave me more confidence..."	Lumpectomy

**Table 3.**

Domain 3: Communication and interaction with the healthcare team

Theme	Quote	Surgery
Communication of surgery-related information and post-surgical expectations	"..even though you hear it...and they kind of describe what to expect, it's...so much information at the time when you're processing so much...it's hard to... really absorb everything."	Bilateral mastectomy with reconstruction
Quality of interaction with the healthcare team/physician	"	
	"... the oncologist and the breast surgeon...they were both on the same page and made it very clear so I could make my decision. They presented all the information and made it clear as they could be."	Unilateral mastectomy with reconstruction

**Table 4.**

Domains 4 and 5: Impact on post-surgical life and recovery and support needs

Theme	Quote	Surgery type
Experiencing physical sequelae	"...they did tell me it would be time-consuming... I couldn't lift my baby – there was lifting restrictions which went on longer than the doctor had said originally..."	Unilateral mastectomy with reconstruction
Adjusting to a new normal	"I lost all my hair, and I had lost so much weight ...I looked like a twelve-year-old boy, and then they took away my breasts, so then I had nothing..."	Bilateral mastectomy without reconstruction
	"...for me, like I have one normal breast and then one that's never going to be normal again..."	Lumpectomy
Adapting to post-surgical challenges	"But then after that, you need to wear other sports bras and things that goes on for a long time, that, that was never really explained."	Bilateral mastectomy with reconstruction
Support received before and after surgery was adequate and helpful for most women	"But I would say our friends were amazing and helping with my children after school when I couldn't drive, and so my husband could be at work...."	Bilateral mastectomy with reconstruction
Support was described as inadequate or not wanted by some women	"I wish I had gone to a support group...I just didn't seek that out. I wish I had done that, though..."	Lumpectomy
Willingness to serve as a resource to others	"I volunteered with my doctors afterward..I actually have been paired up with...women, same age...similar situation... .."	Bilateral mastectomy with reconstruction