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## **Brief Report**

### **Factors affecting surgical decisions in newly-diagnosed young women with early-stage breast cancer**

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**Running head:** Breast cancer surgical decision-making in young women

**Key words:** Breast cancer, surgery, decision making

**Declaration of interests:** None

## **Abstract**

Given that young women with breast cancer often have concerns and priorities attributable to their life stage, we conducted a series of interviews to better understanding the surgical decision-making experience among women diagnosed at age  $\leq 40$ . Women spoke of how the potential effect of an extended recovery was affecting their decision and, in some cases, contributing to decisional conflict. Several women described their worry of leaving cancer cells behind; others cited the need for continued surveillance as a consideration. Attention to situational anxiety and concerns about recurrence is warranted to ensure decisions are made in a supportive and patient-centered setting.

## **Introduction**

In the United States, more than 12,000 women under the age of 40 are diagnosed with breast cancer each year (1). While treatment decisions for breast cancer patients of all ages are affected by multiple factors, young women with breast cancer often have concerns and priorities accentuated by their life stage (e.g., fertility, impact on a young family, starting a career, body image) that may influence their surgical treatment considerations differently than older women.

With more young women with unilateral breast cancer choosing to have contralateral prophylactic mastectomies (CPM), there has been increased attention to this trend. A recent analysis of a nationally representative sample of over 1 million women reporting that the percentage of women who had CPM nearly tripled between 2004 (10.5%) and 2012 (33.3%)(2). CPM decreases the risk of developing a contralateral breast cancer, however for the majority of women (e.g., those without a cancer pre-disposing mutation, such as BRCA1 or BRCA2) this 5-year risk is estimated to be 2-3%(3-5). Additionally, the risk of distant recurrence is the same no matter what breast cancer surgical procedure is chosen, with breast conserving surgery and mastectomy (including CPM) conferring equivalent survival outcomes (6, 7).

Given recent surgical trends in young women with breast cancer, we conducted a series of key informant interviews to gain an in-depth understanding of how newly-diagnosed young women approached decisions about breast cancer surgery.

## **Methods**

Between February and October 2016, we screened Dana-Farber Cancer Institute (DFCI) clinic lists and approached newly-diagnosed women with non-metastatic (Stage 0-III) breast cancer diagnosed at age 40 and younger who had not yet undergone surgery and invited them to participate in a one-time interview study. Interested women who were eligible were

interviewed either in person or via phone. After obtaining informed consent (written for in-person, verbal for phone), interviews were conducted in English except for a single interview conducted in Spanish with the aid of a DFCI institutional interpreter.

A semi-structured interview script (see Appendix) was developed to explore different aspects of the surgical decision-making process. Topics included: sources of information about surgical options, pros and cons of each option, struggles with the surgical decision, physician recommendations, expectations around recovery, genetic testing, and sources of assistance with the decision process. In addition, women were asked for socio-demographic information, clinical stage of disease (if known), and a single question about their preferred medical decision-making style (8). Interviews were expected to take approximately 20 minutes. Participants received a \$25 gift card in appreciation of their time. Interviews were recorded and transcribed with identifiers removed. Following the creation of a preliminary codebook, transcripts were coded by two researchers (SR and MG) using Nvivo software v11 (QSR International, Burlington, MA). Initial codes were classified into preliminary themes and grouped in larger domains using thematic content analysis. Preliminary themes related to the created domain, “factors affecting the surgical decision process,” were subsequently re-classified under broader themes and are presented here. Transcripts also were reviewed for information related to the sources of information and support utilized, and the women’s stage of the decision process at the time of the interview, including whether a participant indicated they had or had not yet made a decision and choice of surgery (if the decision had been made). This research study was approved by the DFCI Institutional Review Board.

## **Results**

Among 20 participants, 20% (4/20) identified as Hispanic or non-White; almost all (18/20) were partnered; median age at interview was 37 (Table 1). At the time of the interview,

50% (10/20) of women reported knowing their clinical stage, with most having Stage 1 or 2 disease (9/10, 90%). A shared decision-making process around surgery was preferred by 45% (9/20) of women; one participant preferred to make the decision about surgical treatment on her own, while 40% (8/20) indicated they preferred making the decision on their own while seriously considering their doctor's opinion.

At the time interview, 60% (12/20) of women indicated they had made a decision about surgery; of these 12, four women said their plan would change if their genetic testing came back positive (Table 2). Among women who had not yet made a decision (n=8), two were leaning towards mastectomy, two were undecided with no preference indicated, and four were waiting for results of their genetic tests before deciding.

Analyses identified six primary themes: 1) post-surgical and survivorship concerns; 2) emotional factors 3) local therapy concerns; 4) reconstruction; 5) recommendations about surgery from providers, family, and friends; 6) family history and genetics. Themes and corresponding sub-themes are presented in Table 3 together with illustrative quotes.

### **Post-surgical and survivorship concerns:**

Future ability to breast feed was a factor for some women in the decision process. Several women cited concerns about how an extended recovery would affect caring for young children and returning to work, and in some cases, contributed to decisional conflict. For example, one woman spoke of how the hardest thing she struggled with regarding her decision was "...trying not to be over reactive in the moment when the decision I make is long-term." In weighing the pros and cons of different types of surgery, one participant spoke of wanting to "choose the easiest, less invasive...that would be the fastest for me to be able to be back to my children" while also acknowledging that a lumpectomy "doesn't feel like... sufficient surgery." Another described how she "worried initially...about the recovery time with the double mastectomy because I do have young kids so that was...daunting."

**Emotional factors/ local therapy concerns/reconstruction:**

The need for peace of mind and concerns about recurrence and contralateral breast cancer also were cited by some women as affecting their decision. Several women spoke of their worry that cancer cells would be left behind after surgery while others cited the need for continued surveillance. Anxiety surrounding frequent mammograms and lack of trust in imaging was also a consideration during the decision process. While issues related to appearance and image were cited as considerations for many women, for others it was not a factor. One woman articulated that she was “not concerned if I’m gonna look ugly...the only concern is my health. But if they give me the opportunity to have reconstructive surgery, of course, I will do it.”

**Recommendations from providers, family and friends:**

Women shared that they received advice or recommendations from a range of sources, including from providers, friends, and family members. One woman described feeling “pressure from my husband to go the lumpectomy route” while another acknowledged “my husband wants me to do them both...I’m just not sure what I want.” Women cited doctors and other providers as being primary sources of information regarding surgical treatment options while partners, other women with breast cancer, and family, friends, and colleagues were identified as being common sources of support or information following diagnosis and during the decision process (Table 2).

**Family history and genetics**

At the time of the interview, some women had already undergone genetic testing and knew their results while others did not yet know their results or had not yet been tested. For many women, knowing the results of their genetic testing – whether positive or negative – did influence surgical decisions, especially whether or not to choose to have a contralateral prophylactic mastectomy.

## Discussion

For young women with recently diagnosed early-stage breast cancer, practical concerns are often weighed in combination with emotional factors when making decisions about surgical treatment. As more young women have chosen to have bilateral mastectomies (6, 7), understanding the implications of extensive surgery, including returning to work and childcare, is essential during the decision-making process. Several young women brought up these concerns when talking about the pros and cons of their surgical options, stressing the importance of these issues. While concerns about the length and intensity of recovery following surgery were reasons for some to consider less extensive surgery, apprehension around the future need for surveillance, worry about recurrence, and peace of mind were reasons some women were considering (and in some cases already had chosen) bilateral mastectomy. Anxiety and worry about recurrence have been found previously to be associated with greater likelihood of overestimation of breast cancer associated risks, including recurrence and contralateral breast cancer, among both women with invasive breast cancer and ductal carcinoma in situ (DCIS) (9-11). Our group and others have previously reported that women cite decreasing their risk of recurrence and contralateral breast cancer, and improving survival as reasons for choosing mastectomy (12-16). The relationship between anxiety and inaccurate risk perceptions as well as the evidence that these factors appear to affect decision-making further underscore the need to account for the role of emotions during a time that can be particularly challenging given there are other treatment-related decisions that are being made. For younger women, this can often include decisions around fertility preservation as well.

Relative to older survivors, younger cancer survivors have been found to have more concerns about recurrence (17), further highlighting the importance of attention to these issues when young women are diagnosed with breast cancer and considering treatment options. While almost half of the women interviewed noted a preference for shared decision-making, an equal number said they preferred to make their surgical decision on their own, though most would



consider their doctor's opinion. These findings suggest that even among women who clearly view the decision as their own, providers still play an influential role in the decision process. This should include not only helping women understand the risks and benefits of different types of breast cancer surgery but also addressing concerns about recurrence and anxiety that may be hindering optimal decision-making.

## **Conclusion**

This was a select population of women who were seen or treated at a comprehensive cancer center and therefore generalizability may be limited. However, while findings from these interviews may not reflect all experiences, they provide insights and add to the available research examining the experiences of young women with breast cancer. In particular, these findings highlight the tension between seemingly conflicting individual priorities and underscore how surgical decisions can be complex for young women with breast cancer due to factors specific to their life stage affecting decision-making.

Developing novel, targeted interventions that deliver relevant information and address situational anxiety as well as concerns about recurrence, may reduce both decisional conflict and distress. Specifically, breast cancer treatment decision aids have been shown to be effective in increasing knowledge and decreasing decisional conflict and are generally well-received by patients (18-21). Additionally, these tools can assist providers with the communication of the pros and cons of different surgical options, including the short and longer-term physical and emotional effects of surgery. One recently developed internet-based decision aid for women thinking about CPM also included strategies to help manage concerns about recurrence as well as concerns related to mammographic surveillance, which were two issues that emerged in our study as affecting decisions (22). Given that concerns about recurrence and cancer worry have been found to be associated with choosing CPM in prior studies(23, 24), addressing anxiety around diagnosis and prognosis in the context of the decision process may

help ensure surgical decisions are both informed and are made in a supportive and patient-centered setting.

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