Why Women Are Choosing Bilateral Mastectomy

Bonnie Jerome-D’Emilia, PhD, MPH, RN, Patricia D. Suplee, PhD, RNC-OB, and Ian D’Emilia, MFA

The rate of women choosing to have a bilateral mastectomy as a treatment for unilateral breast cancer has increased since the 1990s, particularly among younger women. This article describes a qualitative study that was conducted to explore this decision-making process.

At a Glance

- Many women interviewed about their choice to undergo a bilateral mastectomy for the treatment of unilateral breast cancer expressed their desire to never again experience breast cancer.
- The science does not support prophylactic removal of the healthy breast in women diagnosed with unilateral breast cancer who do not have the BRCA1 or BRCA2 mutation.
- Nurses can be advocates for women with breast cancer by acknowledging their concerns, speaking positively about a woman’s right to choose her treatment, and offering comprehensive education so that women can make informed, evidence-based choices.

Evidence-Based Practice

In the 1980s, the results of a large randomized clinical trial of surgical treatment alternatives for early-stage breast cancer found that women who were treated conservatively with a lumpectomy followed by a course of radiation therapy were as likely to survive the disease as were women who had a mastectomy (Fisher et al., 1985). The lumpectomy was significantly less disfiguring, and a woman did not need to consider plastic surgery or a prosthetic device to once again look “normal” in clothes. However, studies found that physicians did not rush to change their practices after the trial results were made public (Mac Bride et al., 2013). As a result, laws were passed in at least 20 states requiring physicians to inform patients of the available surgical options, and women were encouraged to choose their treatment, or at least to play an active role in treatment decision making (Katz & Hawley, 2007). Unlike most diseases, breast cancer, particularly...
TABLE 1. Descriptions of Early-Stage Breast Cancer Types

<table>
<thead>
<tr>
<th>Type and Stage</th>
<th>Description</th>
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<tbody>
<tr>
<td>Ductal carcinoma in situ</td>
<td>Abnormal cells are confined to the milk ducts.</td>
</tr>
<tr>
<td>I</td>
<td>The primary tumor is 2 cm or less in diameter with no lymphatic spread.</td>
</tr>
<tr>
<td>IIA</td>
<td>The tumor is 2–5 cm with no spread to the lymph nodes; or no tumor is found in the breast or the tumor is less than 2 cm, but cancer is found in 1–3 axillary lymph nodes or internal mammary lymph nodes.</td>
</tr>
<tr>
<td>IIB</td>
<td>The tumor is larger than 5 cm without extension into chest wall or skin, and it has spread to 1–9 axillary lymph nodes or internal mammary lymph nodes; or 10 or more nodes are affected; or the tumor is 5 cm or smaller and has spread to 4–9 axillary lymph nodes or it has enlarged the internal mammary lymph nodes.</td>
</tr>
<tr>
<td>IIIA</td>
<td>The tumor is larger than 5 cm without extension into chest wall or skin, and it has spread to 1–9 axillary lymph nodes or internal mammary lymph nodes; or no tumor is found in the breast, but cancer is found in 4–9 axillary lymph nodes or it has enlarged the internal mammary lymph nodes; or the tumor is 5 cm or smaller and has spread to 4–9 axillary lymph nodes or it has enlarged the internal mammary lymph nodes.</td>
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Note. Based on information from the National Cancer Institute, 2015a, 2015b.

at an early stage, is considered to be a preference-sensitive condition in that two or more medically justified treatment options exist: lumpectomy followed by radiation therapy or mastectomy (Wen- nberg, 2002).

The choice to remove both breasts following a cancer diagnosis in one breast has been seen primarily in younger, more educated, insured, and primarily Caucasian women (Pesce et al., 2014; Tracy, Rosenberg, Dominici, & Partridge, 2013). Even women diagnosed with ductal carcinoma in situ, a form of precancer, have been making the decision to remove both breasts (Tuttle et al., 2009). Although women with BRCA mutations have been found to choose this prophylactic surgery as well, most of the women making this choice do not face the increased risk that comes with known genetic mutations. A woman with a BRCA mutation who is diagnosed with a first breast cancer between age 25 years and age 54 years has an 18% 10-year cumulative risk of contralateral breast cancer (Reiner et al., 2013). Removing the unaffected breast reduces this risk by as much as 97%, and for these women, a contralateral mastectomy is considered to be an acceptable risk-reduction strategy (National Comprehensive Cancer Network, 2015b). For a woman who does not carry a genetic mutation and has no family history of breast cancer, the risk of contralateral breast cancer was found to be about 5% (Reiner et al., 2013). In addition, the rate of contralateral breast cancer has been declining in recent years because of the increasing use of adjuvant

TABLE 2. Recommended Clinical Guidelines for Breast Cancer Treatment

<table>
<thead>
<tr>
<th>Type and Stage</th>
<th>Surgical Treatment</th>
<th>Chemotherapy and Radiation Therapy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ductal carcinoma in situ</td>
<td>Lumpectomy and whole breast radiation, or total mastectomy and biopsy of sentinel axillary lymph node</td>
<td>Consider tamoxifen (Nolvadex®, Soltamox®) if estrogen receptor–positive.</td>
</tr>
<tr>
<td>Operable locoregional invasive</td>
<td>Lumpectomy and whole breast radiation, or total mastectomy; axillary lymph node dissection</td>
<td>Postmastectomy radiation therapy if positive lymph nodes; chemotherapy based on hormone receptor status, HER2/neu status, number of positive lymph nodes, and tumor characteristics; tamoxifen and/or aromatase inhibitor treatment if estrogen receptor–positive; trastuzumab (Herceptin®) treatment if HER2/neu positive</td>
</tr>
<tr>
<td>Operable locally advanced invasive</td>
<td>Same surgical treatment as that for operable locoregional invasive</td>
<td>Same chemotherapy and radiation therapy as that for operable locoregional invasive</td>
</tr>
<tr>
<td>Locally advanced invasive</td>
<td>Total mastectomy, or lumpectomy and whole breast radiation depending on size and location of tumor; axillary lymph node dissection</td>
<td>Neoadjuvant or postsurgery chemotherapy based on hormone receptor status; postmastectomy radiation therapy; tamoxifen and/or aromatase inhibitor treatment if estrogen receptor–positive; trastuzumab treatment if HER2/neu positive</td>
</tr>
<tr>
<td>Metastatic</td>
<td>Surgery after systemic treatment if complete local clearance of tumor is possible and if associated with skin ulcera tions, fungation, bleeding, and/or pain</td>
<td>Supportive therapy based on location of metastasis; chemotherapy for estrogen receptor–negative tumors or tumors that do not respond to endocrine therapy; palliative radiation therapy as needed; tamoxifen and/or aromatase inhibitor treatment if estrogen receptor–positive; trastuzumab treatment if HER2/neu positive</td>
</tr>
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</table>

Note. Based on information from the National Comprehensive Cancer Network, 2015a.
TABLE 3. Breast Cancer Screening Guidelines

<table>
<thead>
<tr>
<th>Screening Modalities</th>
<th>Self-Examination</th>
<th>Clinical Examination</th>
<th>Mammography</th>
<th>MRI</th>
<th>Genetic Counseling</th>
</tr>
</thead>
<tbody>
<tr>
<td>Women with an average risk of breast cancer</td>
<td>Be aware of breast changes. Monthly self-examination is optional.</td>
<td>Every 1–3 years when aged 25–40 years; annual examinations when aged older than 40 years</td>
<td>Annually beginning at age 40 years</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>Women with a family history of breast cancer (one or more first-degree relatives with breast cancer)</td>
<td>Be aware of breast changes. Monthly self-examination is optional.</td>
<td>Every 6–12 months starting no later than 10 years before the earliest diagnosis in the family (but not before age 30 years)</td>
<td>Annually beginning 10 years prior to the earliest diagnosis in the family (but not before age 30 years and not later than age 40 years)</td>
<td>Consider annually beginning 10 years prior to the earliest diagnosis in the family</td>
<td>–</td>
</tr>
<tr>
<td>Women with the BRCA1 or BRCA2 mutation</td>
<td>Be aware of breast changes. Monthly self-examination is optional.</td>
<td>Every 6–12 months starting at age 25 years</td>
<td>Annually beginning at age 25 years</td>
<td>Annually beginning at age 25 years</td>
<td>Referral for genetic counseling</td>
</tr>
<tr>
<td>Women with diagnosis of atypical hyperplasia, including lobular carcinoma in situ</td>
<td>Be aware of breast changes. Monthly self-examination is optional.</td>
<td>Every 6–12 months beginning at diagnosis (but not before age 30 years)</td>
<td>Annually beginning at diagnosis (but not before age 30 years)</td>
<td>Consider annually beginning at diagnosis (but not before age 30 years)</td>
<td>–</td>
</tr>
<tr>
<td>Women with previous diagnosis of invasive breast cancer</td>
<td>–</td>
<td>History and physical examination every 4–6 months for 5 years, and then annually</td>
<td>Annually (if previous lumpectomy, first mammogram should be 6–12 months after radiation therapy)</td>
<td>Consider annually for women at high risk of bilateral disease (BRCA positive)</td>
<td>–</td>
</tr>
</tbody>
</table>

MRI—magnetic resonance imaging

Note. Based on information from the National Comprehensive Cancer Network, 2015a, 2015c.


In large national studies, researchers have suggested that women may be overestimating their risk of breast cancer recurrence in the other breast and the resultant risk of death related to a second breast cancer. However, in reality, the spread of the breast cancer to other organs, such as the brain, is more likely to result in a death from breast cancer (Balch & Jacobs, 2009). Table 1 describes the types of early-stage breast cancer, and Table 2 includes the recommended clinical guidelines for the treatment of breast cancer. Given the current evidence, removal of the unaffected breast after a diagnosis of unilateral breast cancer is not medically recommended, regardless of stage, for women who do not carry the BRCA1 or BRCA2 mutation.

**Asking Women Why**

Two of the current authors, both of whom are nursing researchers interested in women’s decision making about breast cancer screening, became curious as to why women were—and are—choosing to remove both of their breasts after a few women close to them opted for this decision. Had these women panicked and rushed into a radical and medically unnecessary decision, or had they made the choice based on what they thought was best? Had they scoured the Internet for information or responded to emotional messages from friends and relatives who had faced a breast cancer recurrence after less radical surgery? Had they received information from their physicians that was comprehensive enough for them to make an informed decision based on their diagnosis and chance of recurrence? These are some of the questions that drove the current authors’ research into women’s decision making.

**Peace of Mind**

The current authors’ qualitative study includes the results of interviews with 23 women from New Jersey and eastern Pennsylvania who had chosen bilateral mastectomies after being diagnosed with unilateral breast cancer (Jerome-D’Emilia, Suplee, Boiler, & D’Emilia, 2015). The women, ranging in age from 30–68 years, spoke of their desire to avoid the follow-up surveillance of the other breast as a major reason for choosing to remove both breasts. One woman stated, “I don’t want to ‘do cancer’ every three to six months.” The current authors found that the women who underwent a bilateral mastectomy had chosen the surgery not because they assumed it was a cure; conversely, all but one of the women in the study expressed fear that the disease would eventually come back in a different part of their body and, at that time, their options would be quite limited. Another woman explained her choice in this way: “The only thing [the doctors] gave me as a sense of peace was that I can do whatever is within my control. . . . [A cancer recurrence somewhere else in the body] is out of my hands, and I can do whatever is within my control.”
... and I won’t have regrets” (Jerome-D’Emilia et al., 2015).

What Are Physicians Telling Women?

Most surprising in the current study was the variability in the women’s recollections of the information they were given by their physicians. Nine women reported that their doctors not only recommended, but also encouraged removal of the unaffected breast. Several women recalled that their physicians gave statistics on recurrence; however, these statistics varied widely and seldom reflected current evidence. Other physicians, as reported by these women, provided personal accounts of what they would do, such as, “If you were my wife, I would tell you to remove both breasts.” None of the women discussed being advised of the potential risks of removing both breasts, described by Khan (2011) as a possible increase in postoperative complications or a decreased satisfaction with sexual pleasure or body image. One woman reported that she asked her surgeon if the “operation would be more difficult.” Her surgeon replied, “Only for me, not for you.” If researchers are concerned that women are basing their choice of surgical procedure on faulty information, then they must consider the fact that some of this information may be coming from physicians. Table 3 describes the screening guidelines for early detection of breast cancer, including the follow-up surveillance for women who have been diagnosed and treated for invasive breast cancer.

In an attempt to curtail the number of bilateral mastectomies being performed on women without medical indication, Katz and Morrow (2013) suggested that perhaps insurance companies should not reimburse surgeons for bilateral procedures as a way to discourage women from making this choice. This suggestion seems to be a coercive and unnecessary infringement of a woman’s right to make an informed choice, and the last thing the current authors want to see is another effort to limit a woman’s right to choose what is right for her life and her body. The current authors’ study suggests that the use of evidence-based medicine when explaining the risks of recurrence and prognosis to a woman newly diagnosed with breast cancer would guide her to make an informed decision in this life-altering treatment option.

Conclusion

Jolie Pitt would certainly agree with women taking an active role in finding out as much as they can about preventive surgery, as well as understanding the pros and cons, the supporting evidence, and the potential risks of the procedure. Nurses and physicians should be advocates for women by providing up-to-date and evidence-based information while supporting a woman’s right to make informed decisions about her body.

References


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**Do You Have an Interesting Topic to Share?**

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